Tony Kershaw
Director of Law and Assurance

If calling please ask for:

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Chichester
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3 March 2020

Health and Adult Social Care Scrutiny Committee

A meeting of the committee will be held at **10.30 am** on **Wednesday, 11 March 2020** at **County Hall, Chichester PO19 1RQ**.

Tony Kershaw
Director of Law and Assurance

The meeting will be available to view live via the Internet at this address:

http://www.westsussex.public-i.tv/core/portal/home

Agenda

10.30 am 1. **Declarations of Interest**

Members and officers must declare any pecuniary or personal interest in any business on the agenda. They should also make declarations at any stage such an interest becomes apparent during the meeting. Consideration should be given to leaving the meeting if the nature of the interest warrants it. If in doubt please contact Democratic Services before the meeting.

10.32 am 2. **Urgent Matters**

Items not on the agenda which the Chairman of the meeting is of the opinion should be considered as a matter of urgency by reason of special circumstances, including cases where the Committee needs to be informed of budgetary or performance issues affecting matters within its terms of reference, which have emerged since the publication of the agenda.

10.33 am 3. **Minutes of the last meeting of the Committee** (Pages 5 - 8)

The Committee is asked to agree the minutes of the meeting held on 15 January 2020 (cream paper).

10.35 am 4. **Responses to Recommendations** (Pages 9 - 16)

The Committee is asked to note the responses to recommendations made at its 15 January 2020 meeting from: -

a) The Cabinet Member for Adults & Health
b) The Chief Executive of Sussex Partnership NHS Foundation Trust
c) The Chief Executive of Western Sussex Hospitals NHS Foundation Trust

10.40 am 5. **Forward Plan of Key Decisions** (Pages 17 - 28)

Extract from the Forward Plan dated 2 March 2020.

An extract from any Forward Plan published between the date of despatch of the agenda and the date of the meeting will be tabled at the meeting.

The Committee is asked to consider whether it wishes to enquire into any of the forthcoming decisions within its portfolio.

10.50 am 6. **Self-harm and West Sussex Suicide Prevention Strategy Priorities** (Pages 29 - 38)

Report by Director of Public Health.

The report outlines current activity to address self-harm in the county and additional proposed strategic priorities to be included in the updated West Sussex Suicide Prevention Strategy.

11.35 am 7. **West Sussex Joint Dementia Strategy 2020-23** (Pages 39 - 104)

Report by Executive Director, Adults and Health.

The strategy sets out the Council's and Clinical Commissioning Group's commitments and provides a framework for further action to ensure the realisation of the vision for dementia in West Sussex.

12.20 pm 8. **Proposals to improve mental health services in West Sussex** (To Follow)

Report to follow.

12.50 pm 9. **Appointment to Business planning Group**

The Committee is asked to appoint a county councillor from a minority group to fill a vacancy on its Business Planning Group.

12.52 pm 10. **Possible Items for Future Scrutiny**

Members to mention any items which they believe to be of relevance to the business of the Scrutiny Committee, and suitable for scrutiny, e.g. raised with them by constituents arising from central government initiatives etc.

If any member puts forward such an item, the Committee's role at this meeting is just to assess, briefly, whether to refer the matter to its Business Planning Group (BPG) to consider in detail.

12.54 pm 11. **Requests for Call-in**

There have been no requests for call-in to the Scrutiny Committee and within its constitutional remit since the date of the last meeting. The Director of Law and Assurance will report any requests since the publication of the agenda papers.

12.55 pm 12. **Date of Next Meeting**

The next meeting of the Committee will be held on 10 June 2020 at 10.30 am at County Hall, Chichester. Probable agenda items include:

- Social Isolation / Contract arrangements for Social Support Services
- Improved Better Care Fund
- Safeguarding Adults Board Annual Report

Any member wishing to place an item on the agenda for the meeting must notify the Director of Law and Assurance by 26 May 2020.

To all members of the Health and Adult Social Care Scrutiny Committee

Webcasting

Please note: this meeting may be filmed for live or subsequent broadcast via the County Council's website on the internet - at the start of the meeting the Chairman will confirm if all or part of the meeting is to be filmed. The images and sound recording may be used for training purposes by the Council.

Generally the public gallery is not filmed. However, by entering the meeting room and using the public seating area you are consenting to being filmed and to the possible use of those images and sound recordings for webcasting and/or training purposes.

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Health and Adult Social Care Scrutiny Committee

15 January 2020 – At a meeting of the Health and Adult Social Care Scrutiny Committee held at 10.30 am at County Hall, Chichester.

Present:	Mr Turner (Chairman)	
Dr Walsh	Ms Flynn	Katrina Broadhill
Mrs Arculus	Mrs Jones	Cllr Bangert
Lt Cdr Atkins	Mr Markwell	Cllr Bennett
Mr Boram	Dr O'Kelly	Cllr McGregor
Mrs Bridges	Mr Wickremaratchi, arrived at 10.40	

Apologies were received from Cllr Bickers and Cllr Peacock

Absent: Mrs Smith and Cllr McAleney

Also in attendance: Mrs Jupp

34. Declarations of Interest

34.1 In accordance with the code of conduct, Mrs Bridges declared a personal interest in item 4, Adults' Services Improvement - Next Steps, as she has a family member in a residential home in West Sussex.

35. Minutes of the last meeting of the Committee

35.1 Resolved – that the minutes of the meeting held on 27 November 2019 be approved as a correct record and that they be signed by the Chairman.

36. Adults' Services Improvement - Next Steps

36.1 The Committee considered a report by the Executive Director Adults and Health (copy appended to the signed minutes) which was introduced by Mrs Jupp, Cabinet Member for Adults & Health who told the Committee: -

- In Summer 2019 pressures in Adults' Services led to Newton being appointed to carry out a diagnostic across Adults' and Lifelong Services to identify ways to improve outcomes for people and identify ways of more cost-effective working

36.2 Kim Curry, Executive Director for Adults & Health, added: -

- Newton's work enhanced that of the Council's Transformation Team
- Adults' Services was now safe, although West Sussex was still behind some other authorities

36.3 Steve Phillips and Laps Senthilgiri of Newton took the Committee through a presentation (copy appended to the signed minutes) on the work Newton had carried out in collaboration with Adults' Services using workshops with Council staff and surveys of customers, families and professionals.

36.4 Summary of responses to the Committee's questions and comments: -

- The criteria for deciding if a customer outcome was ideal or non-ideal was decided by the Council's social workers
- Families and health professionals might be reluctant to advocate any type of care at home as they might not be familiar with its quality or availability
- People could be reluctant to refer customers for reablement services due to previous experience, lack of availability, quality of service or pressure to make a quick decision
- Reablement services would be time limited
- A customer's hospital stay should not be the basis for a decision on long-term care, but should be an influence
- Care packages were reviewed between six weeks and two months after implementation, at the annual review and if a person's condition changed
- All operational and commissioning requirements had been considered
- Four options were being considered for the way forward, but the Council does not have the capacity or capability to deliver the programme alone
- There were savings to be made by moving away from dependent to independent services such as reablement, but to reach the level of service required an investment of £1.4m would be needed in reablement
- The Adult Social Care Improvement Board had instigated five safety indicators – performance against these showed the services was safe, especially in regard to safeguarding and assessments of deprivation of liberty standards – **ACTION**: Kim Curry to provide detailed data on the five safety indicators
- There needed to be changes in the leadership and management teams as well as investment in training and development of the workforce so that staff felt more supported – the Department of Health & Social Care was encouraged that the Council was working with Newton
- Connecting Lives, Supporting people fitted the proposals and identified local voluntary services
- The Council was working with district and borough councils to hasten adaptations (if needed) so that people could return home from hospital as soon as possible
- Newton has worked with 42 other authorities, 40 of which took them on to help deliver adult social care, one did not, and one has yet to decide
- The Cabinet was committed to this way of working going forward
- Pending decisions would not be affected by this work
- This approach should make the adult social care budget more sustainable

36.5 – Resolved that the Committee: -

i. Supports the development of the diagnostic work assured by the due diligence as set out in the report if Newton is appointed as a strategic partner moving forwards, however it raises concerns over the capacity and capability of the reablement and care & support at home market to deliver deserved outcomes
ii. Highlights the importance of working with partners, especially the NHS, when developing this work
iii. Highlights the importance of supporting and developing frontline staff throughout
iv. Seeks assurance that customers are part of any co-production carried out as part of this work
v. Asks for a commitment at a strategic level that this be a long-term project
vi. Asks that the Committee has the opportunity to scrutinise this work throughout its development

37. Responses to Recommendations and Updates to Actions

37.1 The Committee considered responses to recommendations from its last meeting and had concerns over the take-up of flu vaccinations by hospital staff – **ACTION**: Mrs Jupp to raise the possibility of hospital staff receiving flu vaccination vouchers at the next meeting of the Health & Wellbeing Board.

37.2 The Committee considered updates to actions from its last meeting and raised concerns over the staff vacancy rates at Sussex Partnership NHS Foundation Trust and Western Sussex Hospitals NHS Foundation Trust.

37.3 Resolved - that the Committee: -

i. Notes the responses to recommendations
ii. Asks the Chairman to write to Sussex Partnership NHS Foundation Trust and Western Sussex Hospitals NHS Foundation Trust regarding their staff vacancy rates

38. Forward Plan of Key Decisions

38.1 Resolved – that the Committee notes the Forward Plan of Key Decisions.

39. Business Planning Group Report

39.1 The Committee considered a report by the Chairman of the Business Planning Group (copy appended to the signed minutes) and requested that the future item on access to primary care include information from Healthwatch on waiting times and queried whether the item on low vision services would include cataracts and star guards – **ACTION:** Helena Cox to check the scope of low vision services

39.2 Resolved – that the Committee endorses the contents of the report, and the Committee's Work Programme.

40. Possible Items for Future Scrutiny

40.1 The following items were suggested for future scrutiny: -

- NHS Human Resources Strategy
- NHS Dentistry

41. Date of Next Meeting

41.1 The next meeting of the Committee will take place on 11 March.

The meeting ended at 1.26 pm

Chairman

Responses to recommendations

Recommendations to the Cabinet Member for Adults & Health	**Responses from the Cabinet Member for Adults & Health**
The Committee: - i. Supports the development of the diagnostic work assured by the due diligence as set out in the report if Newton is appointed as a strategic partner moving forwards, however it raises concerns over the capacity and capability of the reablement and care & support at home market to deliver deserved outcomes ii. Highlights the importance of working with partners, especially the NHS, when developing this work iii. Highlights the importance of supporting and developing frontline staff throughout iv. Asks that the Committee has the opportunity to scrutinise this work throughout its development v. Seeks assurance that customers are part of any co-production carried out as part of this work vi. Asks for a commitment at a strategic level that this be a long-term project	I thank the Health & Adult Social Care Scrutiny Committee (HASC) for its recommendations and support and also for its detailed and enthusiastic questions. I am committed to making sure that the HASC recommendations are taken forward in the next stage of transformation and am keen that they play a key role in scrutinising progress. Further, we are committed to co-production with our customers, their carers and families and with our NHS partners and wide stakeholders, particularly the community and voluntary sector recognising the reliance on building community resilience. Our staff are our greatest asset and again we are committed to supporting them to develop with confidence and deliver the transformational change that they have participated in the assessment of so enthusiastically. Finally, in my role as cabinet member, I will do everything I can to make sure that this credible programme is implemented as a long-term plan and built into our financial and resource assumptions as such.
Recommendations to the Chief Executive of Sussex Partnership NHS Foundation Trust The Committee asks the Chairman to write to Sussex Partnership NHS Foundation Trust and Western Sussex Hospitals NHS Foundation Trust regarding their staff vacancy rates	**Responses from the Chief Executive of Sussex Partnership NHS Foundation Trust** See separate paper

Recommendations to the Chief Executive of Western Sussex Hospitals NHS Foundation Trust	**Responses from the Chief Executive of Western Sussex Hospitals NHS Foundation Trust**
The Committee asks the Chairman to write to Sussex Partnership NHS Foundation Trust and Western Sussex Hospitals NHS Foundation Trust regarding their staff vacancy rates	See separate paper

ıember of:
Association of UK University Hospitals

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Private & Confidential
Mr Bryan Turner
Chairman
Health and Adult Social Care Scrutiny Committee
County Hall
Wall Street
Chichester
West Sussex
PO19 1RQ

13 February 2020

Dear Bryan

Re. Recommendations from Health & Adult Social Care Scrutiny Committee - 15 January 2020

Thank you for your letter dated 24 January 2020 raising the issue of nursing staff vacancies across West Sussex.

In your letter you detail the vacancy rates for the Trust, however, these were incorrect. I have provided the latest vacancy data below for information:

	Nursing - qualified	Ancillary - non qualified (HCA)	Medical	Allied e.g. Psychologist/ OT etc.
SPFT West Sussex	17.50%	5.91%	25.75%	3.65%
SPFT Trust wide- Operational	15.80%	13.62%	16.06%	4.91%

In terms of the actions the Trust is taking to reduce the current level of vacancies I can confirm a number of initiatives have been developed. These include:

- Focused recruitment campaigns in priority areas with increased use of radio advertising, social media and advertising at areas of high usage such as bus stops and on the side of public transport.
- A £2,000 golden hello for new nurses.
- Fast track career progression scheme.

- Improved flexible working arrangements.

- Funded Return to Practice training for nurses who have left the profession but want to return

- A Refer a Nursing Friend scheme has also been launched across the organisation, where existing staff could be paid up to £1,000 for successfully helping to identify new staff

- Active recruitment of Trainee Nursing Associates to improve the longer term pipeline for qualified nurses.

In addition through our Nursing Strategy, we are working with Brighton University to support Return to Practice Nurses, retain nursing students on completion of their training, and are attending careers fairs at various Universities across the UK to attract staff to work for the Trust.

To improve retention, we are addressing how we support our nurses in their clinical career pathways with preceptorship, mentorship and a Band 5/6 development programme Additionally, we are also encouraging new roles such as Mental Health Graduate Practitioners, Peer Support Workers and Nursing Associates to enhance skill mix and patient care time.

In terms of recruitment to our medical vacancies we have been undertaking the following actions:

- Developing a programme which will support Specialty Doctors and Associate Specialist grades to become Consultants. Whilst this does not create an immediate solution, it will be important for attracting and retaining doctors as well as developing consultants for the future.

- A continued recruitment campaign focusing on Adults and CAMHS services based in West Sussex.

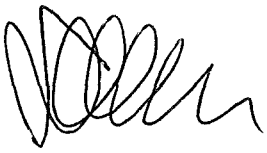
- A Relaunch of the Medical Bank to reduce dependency on agency and also to provide a recruitment pipeline for individuals who may be interested in joining the Trust but want to gain some experience of working in the organisation first

The work that the Trust is undertaking on medical recruitment is having a positive impact. 3 full time Speciality Doctors and 1 Consultant are due to join the Trust in February and a further 1.6 Specialty Doctors and 3 2 Consultants are currently undergoing employment checks before a start date is confirmed.

Of these new appointments, 4.6 will be based in West Sussex. This is very positive given the national supply issues in certain specialities. I also wish to highlight that whilst a post is vacant, 'locum' cover arrangements are in place to meet patient care.

I hope this information provides you with assurance that the Trust is taking ongoing steps to reduce its vacancies. Should you require any further information, please do not hesitate to let me know

Yours sincerely



Samantha Allen
Chief Executive

CC: Pennie Ford, Coastal West Sussex CCGs

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Western Sussex Hospitals
NHS Foundation Trust

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Worthing
West Sussex
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Tel: 01903 205111
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2nd March 2020

Mr Bryan Turner - Chairman
Health and Adult Social Care Scrutiny Committee
West Sussex County Council
County Hall
West Street
Chichester
West Sussex, PO19 1RQ

Dear Bryan

I am writing in response to your letter dated 24th January 2020 regarding our vacancy levels. You have asked for a response outlining the actions being taken by the Trust to address these.

The Trust has a good stable workforce and we have had fantastic success with our international recruitment. We intend to build on this success alongside a strong domestic recruitment campaign. Whilst maintaining a strong focus on recruiting the best people we supplement this and maintain flexibility through our high calibre temporary workforce.

However, as you will be aware there are high levels of vacancy across the NHS, with a number of nationally and regionally identified staff shortages. There is work underway at both a national and local level to address these issues. We can assure you that we are also actively taking all steps to reduce our vacancy levels and review our plans and initiatives on a regular basis. Recruitment initiatives in place include:

- ongoing overseas recruitment
- review of recruitment methods and materials to ensure we are reaching all possible candidates
- successful targeted approaches to temporary staff to transfer into substantive posts
- redesign of vacant posts to attract candidates and develop career academic pathways
- review and introduction of new roles and ways of working including Physician Assistants, Surgical Care Practitioners, enhanced AHP roles, Nurse Associates and a range of apprenticeships
- ensuring an attractive offer for new recruits including flexible working options
- Refer a friend scheme

In addition to taking steps to recruit staff we also have initiatives in place to retain our workforce. These include carrying out stay interviews with our staff to identify and address any triggers for leaving, focus on initiatives to improve staff engagement and health and wellbeing. Our turnover rate has been reducing over the course of the last 12 months and is now at 6.9%. This is currently the lowest rate within the ICS. We have also seen positive improvements in our latest staff survey results for staff intention to leave the organisation. We have seen a 3% reduction in staff indicating they intend to leave compared to last year and our results are 6% lower than the national average for acute Trusts.

It is important to note that we also have a strong temporary workforce and our vacancy rate when taking this workforce into account has been 2.5% for the financial year to date.

I hope this provides the reassurance you require regarding the measures being taken by the Trust, but should you require further detail please do not hesitate to contact me.

Yours sincerely

Maggie Davies
Chief Nurse

Forward Plan of Key Decisions

The County Council must give at least 28 days' notice of all key decisions to be taken by members or officers. The Plan describes these proposals and the month in which the decisions are to be taken over a four-month period. Decisions are categorised according to the West Sussex Plan priorities of:

- **Best Start in Life** (those concerning children, young people and schools)
- **A Prosperous Place** (the local economy, infrastructure, highways and transport)
- **A Safe, Strong and Sustainable Place** (Fire & Rescue, Environmental and Community services)
- **Independence in Later Life** (services for older people or work with health partners)
- **A Council that Works for the Community** (finances, assets and internal Council services)

The most important decisions will be taken by the Cabinet sitting in public. The schedule of monthly Cabinet meetings is available on the website. The Forward Plan is updated regularly and key decisions can be taken on any day in the month if they are not taken at Cabinet meetings. The Plan is available on the County Council's website and from Democratic Services, County Hall, West Street, Chichester, PO19 1RQ, all Help Points and the main libraries in Bognor Regis, Crawley, Haywards Heath, Horsham and Worthing. Published decisions are also available via the website.

A key decision is one which:

- Involves expenditure or savings of £500,000 or more (except treasury management); and/or
- Will have a significant effect on communities in two or more electoral divisions in terms of how services are provided.

The following information is provided for each entry in the Forward Plan:

Decision	A summary of the proposal.
Decision By	Who will take the decision - if the Cabinet, it will be taken at a Cabinet meeting in public.
West Sussex Plan priority	Which of the five priorities in the West Sussex Plan the proposal affects.
Date added	The date the proposed decision was added to the Forward Plan.
Month	The decision will be taken on any working day in the month stated. If a Cabinet decision, it will be taken at the Cabinet meeting scheduled in that month.
Consultation/ Representations	How views and representations about the proposal will be considered or the proposal scrutinised, including dates of Scrutiny Committee meetings.
Background Documents	The documents containing more information about the proposal and how to obtain them (via links on the website version of the Forward Plan). Hard copies are available on request from the decision contact.
Author	The contact details of the decision report author
Contact	Who in Democratic Services you can contact about the entry

Finance, assets, performance and risk management

Each month the Cabinet Member for Finance reviews the Council's budget position and may take adjustment decisions. A similar monthly review of Council property and assets is carried out and may lead to decisions about them. These are noted in the Forward Plan as 'rolling decisions'.

Each month the Cabinet will consider the Council's performance against its planned outcomes and in connection with a register of corporate risk. Areas of particular significance may be considered at the scheduled Cabinet meetings.

Significant proposals for the management of the Council's budget and spending plans will be dealt with at a scheduled Cabinet meeting and shown in the Plan as strategic budget options.

For questions contact Helena Cox on 033 022 22533, email helena.cox@westsussex.gov.uk.

Published: 2 March 2020

Forward Plan Summary

Summary of all forthcoming executive decisions in West Sussex Plan priority order

Page No	Decision Maker	Subject Matter	Date
 **A Strong, Safe and Sustainable Place**			
	Executive Director Adults and Health	Extension of Day Services Contracts (Adults with Learning Disabilities)	March 2020
	Executive Director Adults and Health	Procurement Housing Related Support Services	March 2020
	Executive Director Adults and Health	Specialist Advocacy Service Award of Contract	March 2020
	Cabinet Member for Adults and Health	Supported Living Services Procurement	March 2020
 **Independence in Later Life**			
	Executive Director Adults and Health	Extension of the Community Equipment Service Contract	March 2020
	Cabinet Member for Adults and Health	Review of fees and charges for commissioned services	March 2020
	Cabinet Member for Adults and Health	Commissioning of Extra Care Contracts	March 2020
	Executive Director Adults and Health	Discharge to Assess with Reablement Care Services	March 2020
	Cabinet	Adults' Services Improvement - Next Steps	April 2020
 **A Council that works for the Community**			
	Cabinet Member for Adults and Health	Procurement of Mortuary Services	March 2020

A Strong, Safe and Sustainable Place

Executive Director Adults and Health

Extension of Day Services Contracts (Adults with Learning Disabilities)
Learning disability day services are delivered through contracts with 9 independent organisations. These services, along with the Council's in-house day services, meet customers social care needs, as defined under the Care Act 2014, by promoting independent living and wellbeing by providing a range of functions: • Support to those that struggle to access their community independently and for those with complex physical needs - personal and/or practical care at the day centre; • Training and skills development to support independence; • Work based training and support to enable people to move into supported or open employment; • Coordination of social and recreational activities; • Provision of a meeting place to build relationships beyond those with carers and staff, thus reducing social isolation and loneliness; • Supported stimulating activities for people with profound multiple disabilities; and • Carers respite. Taking up the extension will allow the County Council and its health partners to explore future delivery models and associated cost structures which, in line with the Lifelong Disability and Autism Market Position Statement objectives, will lead to new models of support which focus on progression, increased independence and community based relationships resulting in a reduction of building base day services. The contracts with the independent providers were let on a 5 year term, commencing 1st April 2015, with the option for a 2 year extension (Decision Ref: HA11 12/13). The Executive Director Adults and Health is asked to extend the contracts with the independent providers for a further two years to 31 March 2022.

Decision by	Kim Curry - Executive Director Adults and Health
West Sussex Plan priority	A Strong, Safe and Sustainable Place
Date added	12 February 2020
Month	March 2020
Consultation/ Representations	Representations concerning this proposed decision can be made to the Executive Director for Adults and Health via the officer contact.
Background Documents (via website)	None
Author	Karen Young Tel: 0330 022 23794
Contact	Erica Keegan Tel: 0330 022 26050

Executive Director Adults and Health

Procurement Housing Related Support Services	
The current housing related support contractual arrangements from the 1st October 2019 were approved by the Executive Director of Adults and Health (Decision Ref: OKD13 19/20). The services were recommissioned based on a revised financial envelope and were prioritised as green, amber and red, based on a strategic fit to the Council's priorities. Amber services, listed within report OKD13/1920, have been remodelled and recommissioned. This commissioning is based on the outcome of a partnership task and finish working group, which included representatives from the County Council and the District and Borough councils. In September 2019, the District and Borough partners committed to co-fund the services from 1st October 2020. The extension of contracts for Amber Priority services were agreed until 31st March 2020. Following this the Director of Law and Assurance has agreed a Single Tender Waiver for 3 'Amber' Housing Related Support services with contracts to commence 1st April 2020 for a period of 6 months only. These short term single tenders will enable the council to run a full competitive tender, in partnership with District and Borough colleagues, as agreed by the Executive Director of Adults and Health (Decision Ref: OKD13 19/20) starting in March 2020, with new contracts starting on 1st October 2020. For this there will be a West Sussex County Council financial envelope of £350k per annum. This equates to £50k per District and Borough area. This funding will be matched by the relevant District or Borough Council. The Executive Director Adults and Health will be asked to approve the commencement of a Procurement for Housing Related Support Services in West Sussex. The tender will be divided into 6 lots: o Adur/Worthing – Indicative Contract Value = £200,000 per annum o Chichester - Indicative Contract Value = £100,000 per annum o Crawley - Indicative Contract Value = £100,000 per annum o Horsham - Indicative Contract Value = £100,000 per annum o Mid Sussex – Indicative Contract Value = £100,000 per annum o Arun – Indicative Contract Value = £100,000 per annum In Adur/Worthing, Chichester, Crawley and Horsham, the services will be based on a floating support model and will be tenure neutral. In Mid Sussex and Arun, the service will be mainly accommodation based and bidders must be able to provide at least 10 units of accommodation.	
Decision by	Kim Curry - Executive Director Adults and Health
West Sussex Plan priority	A Strong, Safe and Sustainable Place
Date added	25 February 2020
Month	March 2020
Consultation/ Representations	Consultation: • Partnership task and finish group including district and borough council representatives • Health and Adult Social Care Select Committee – 12 June 2019

	Representations concerning this proposed decision can be made to the Executive Director Adults and Health, via the officer contact.
Background Documents (via website)	None
Author	Sarah L Leppard Tel: 0330 022 23774
Contact	Erica Keegan Tel:0330 022 26050

Executive Director Adults and Health

Specialist Advocacy Service Award of Contract	
The Specialist Advocacy Service will support customers with significant communication difficulties to have a voice and express their needs and wishes. Customers will be supported to resolve issues and difficulties which would otherwise have a negative impact on their physical and mental well-being. This Advocacy Service is a component part of the People Services prevention strategy which is designed to support demand management and delivery of value for money. It acts as an effective shield to costly frontline services and supports customers to resolve issues and difficulties independently, or with the support of an advocate. Following the Cabinet Member for Adults and Health's decision, in October 2019 (AH8 19/20) , to commence a competitive procurement exercise for a Specialist Advocacy Service, a robust open tender procurement process in compliance with West Sussex County Council Standing Orders on Procurement and Contracts has been undertaken. The procurement attracted competitive bids which have been evaluated robustly on both technical and financial aspects. Prior to commencement of evaluation, it was agreed that the contractor submitting the most economically advantageous tender would be recommended for award of the contract and a successful bidder has been identified. The Executive Director Adults and Health seeks to award the contract to the successful bidder and to extend the contract, if appropriate, in accordance with the County Council's Standing Orders on Procurement and Contracts, subject to this being affordable within the limits of planned budgets.	
Decision by	Kim Curry - Executive Director Adults and Health
West Sussex Plan priority	A Strong, Safe and Sustainable Place
Date added	20 January 2020
Month	March 2020
Consultation/ Representations	Representations concerning this proposed decision can be made to the Executive Director of Adults and Health via the officer contact, by the beginning of the month in which the decision is due to be taken.
Background Documents (via website)	None

Author	Liz Merrick Tel: 033 022 23733
Contact	Erica Keegan Tel: 0330 022 26050

Cabinet Member for Adults and Health

Supported Living Services Procurement	
Supported Living services are care, support and accommodation services purchased by the Council on behalf of people who have been assessed as having eligible social care needs. These services support people to live more independently through the provision of personal care and outreach support. The council currently commissions the majority of these services from a framework agreement which first commenced in April 2012 (Supported Living & Personal Support for Adults with Learning Disability Framework). In 2016 a new framework was let (Supported Living and Family Support Services for adults with learning disabilities and disabled children and young people in West Sussex Framework). This framework ends in March 2021. The commissioning of supported living is being reviewed with proposals being developed for new arrangements to be established across the county which will enable the achievement of our strategic aim to support more people to live in settled accommodation, with their family or in their own tenancy, for longer. The council will develop new arrangements considering: the challenges faced in the market - particularly around recruitment and retention of staff; the provision for increasingly complex individuals; the need to strengthen community networks and maximise customer independence; and develop services which meet the expectations of customers and their families. Following the review and wide-ranging stakeholder engagement, the Cabinet Member for Adults and Health will be asked to approve the commencement of a procurement process to source the future supported living services and delegate authority for Contract Award to the Executive Director Adults and Health.	
Decision by	Mrs Jupp - Cabinet Member for Adults and Health
West Sussex Plan priority	A Strong, Safe and Sustainable Place
Date added	16 October 2019
Month	March 2020
Consultation/ Representations	Key Stakeholder engagement will inform this procurement including an online survey and market event. Representations concerning this proposed decision can be made to the Cabinet Member for Adults and Health, via the officer contact, by the beginning of the month in which the decision is due to be taken.
Background Documents (via website)	None

Author	Alison Nuttall Tel: 033 022 25936
Contact	Erica Keegan Tel: 033 022 26050

Independence in Later Life

Executive Director Adults and Health

Extension of the Community Equipment Service Contract	
The Community equipment service (CES) is delivered through a contract with Nottingham Rehab Ltd (trading as NRS Healthcare). The service meets customers social care needs as defined under the Care Act 2014 by promoting independent living and wellbeing. The contract was let on a 5 year term, commencing 1 April 2015, with the option for a 2 year extension. It is recommended that the County Council take up the opportunity to extend for a further two years to 31 March 2022. Taking up the extension will allow the County Council and its health partners to explore future delivery models, including potential collaborative arrangements with other local authorities.	
Decision by	Kim Curry - Executive Director Adults and Health
West Sussex Plan priority	Independence in Later Life
Date added	27 December 2019
Month	March 2020
Consultation/ Representations	Representations concerning this proposed decision can be made to the Executive Director for Adults and Health via the officer contact, by the beginning of the month in which the decision is due to be taken.
Background Documents (via website)	Original Decision Report - ASCH05(13/14)
Author	Jane Walker Tel: 033 022 27927
Contact	Erica Keegan Tel: 033022 26050

Cabinet Member for Adults and Health

Review of fees and charges for commissioned services
The Cabinet Member will be asked to consider the fees and rates paid for commissioned services related to the Adult Social Care and Health portfolio for 2020-21. This will cover all services commissioned for older people and adults with either a learning disability, physical disability or mental health condition. The review will consider usual maximum rates for care homes and care homes with nursing; individually agreed rates paid to care

homes and care homes with nursing; shared lives; and rates and fees paid for community-based services.	
Decision by	Mrs Jupp - Cabinet Member for Adults and Health
West Sussex Plan priority	Independence In Later Life
Date added	24 January 2020
Month	March 2020
Consultation/ Representations	Representations concerning this decision can be made to the Cabinet Member for Adults and Health, via the Officer Contact.
Background Documents (via website)	None
Author	Debbie Young Tel: 033 022 24134
Contact	Erica Keegan Tel: 0330 022 26050

Cabinet Member for Adults and Health

Commissioning of Extra Care Contracts
West Sussex County Council are working in partnership with District & Borough Councils, registered housing providers and registered care providers to develop and deliver extra care housing across West Sussex. The Council have commissioned care provision within 12 existing extra care services and are now looking to commence a procurement to source care provision for two new extra care housing schemes. Extra care housing provides specialist accommodation to adults primarily over the age of 55 years who require adapted properties and have eligible care and support needs as assessed in line with the Care Act 2014. The schemes provide individual adapted apartments, communal areas, a restaurant and an onsite care team. Extra care housing is enabling residents of West Sussex to remain independent within their communities and provides an alternative option to residential care. In 2017, Following a key decision by the Cabinet Member for Adults and Health,(Ref: ASCH916-17) the Council set up a new dynamic purchasing system (DPS) framework for extra care housing. The DPS allows the Council to approve and add new appropriately qualified care providers to the framework at any time. All providers on the DPS will meet core requirements. When new schemes are developed or there is a need for a change of care provider in an existing scheme, the DPS will be used to source the care provision. Alongside the DPS, the 12 current schemes were awarded new care contracts for 3 years with the possibility of a further 2-year extension. Since the commencement of the DPS two new extra care schemes have been in development with building work having now commenced on both. Monaveen in Westergate will open to its first residents in December 2020 and Lingfield Lodge in East Grinstead will be completed in March 2021. The Cabinet Member for Adults and Health will be asked to agree the extension of the current contracts for existing services, extension of the DPS framework, and approval to

commence a procurement process through the DPS to source the future care provision for the two new schemes. Following procurement, the Cabinet Member for Adults and Health will be asked to delegate authority for contract award to the Executive Director Adults and Health.	
Decision by	Mrs Jupp - Cabinet Member for Adults and Health
West Sussex Plan priority	Independence in Later Life
Date added	3 February 2020
Month	March 2020
Consultation/ Representations	Utilised Internal Officer Specialisms Representations concerning this proposed decision can be made to the Cabinet Member for Adults and Health via the officer contact.
Background Documents (via website)	
Author	Carrie Anderson Tel: 0330 022 22996
Contact	Erica Keegan Tel: 0330 022 26050

Executive Director Adults and Health

Discharge to Assess with Reablement Care Services
Discharge to Assess with Reablement services are designed for hospital patients who are medically fit for discharge, but unable to immediately return home; it is a model recognised by NHS England as facilitating earlier discharge and/or reducing the number and length of delays in discharge from hospital for older people. The key objectives delivered through Discharge to Assess are: • Reduction of delayed transfers of care (DTOC) between health and social care; • reduced level of dependency for as many customers as possible; • ensuring that no long-term decisions concerning customers' care needs are made in an acute setting Contracts for the provision of Discharge to Assess with Reablement services were awarded in 2018, for an initial fixed term of 2-years with options to extend to a maximum of 5-years, through an EU Procurement exercise conducted following approval of Cabinet Decision AH01 17-18. The initial contract term comes to an end on 31st March 2020, an extension of 2-years has been requested by Adults Operations to support the Adults and Health Step-Up, Step-Down programme. The Executive Director Adults and Health will be asked to agree the extension of the existing contracts for 2-years, commencing 1 April 2020.

Decision by	Kim Curry - Executive Director Adults and Health
West Sussex Plan priority	Independence in Later Life
Date added	5 February 2020
Month	March 2020
Consultation/ Representations	Representations concerning this proposed decision can be made to the Executive Director Adults and Health via the officer contact, by the beginning of the month in which the decision is due to be taken.
Background Documents (via website)	None
Author	Lee Jenner Tel: 0330 022 23754
Contact	Erica Keegan Tel: 0330 022 26050

Cabinet

Adults' Services Improvement - Next Steps	
In 2018 in response to identified pressures and service challenges within adult social care a peer challenge led to a 100-day plan of action followed by a three-year programme of improvement structured around 100-day milestones starting in November 2018. By the start of the improvement programme the service was in a better position and that progress has continued. During the summer of 2019 the service faced additional operational pressures and the improvement programme was refocused towards helping to address those. In October 2019 in order to increase the scale and pace of delivery, the Council appointed a strategic partner to carry out a diagnostic assessment across both Adults' and Lifelong Services to identify ways to improve service outcomes for people whilst identifying opportunities for more cost-effective ways of working. The output from this work describes the challenges facing the services and the specific actions that would deliver long-term cost effective and sustainable improvement. The Cabinet will be asked to consider the outputs from this diagnostic assessment and agree the next stages for the ongoing improvement of the Adults' and Lifelong Services including the procurement of activity to drive their delivery.	
Decision by	Mrs Jupp - Cabinet
West Sussex Plan priority	Independence in Later Life
Date added	5 December 2019
Month	April 2020

Consultation/ Representations	Health and Adult Social Care Scrutiny Committee – 15 January 2020 (to consider the diagnostic assessment and scope of further work prior to commencement) or through short form task group direct to Cabinet Member prior to decision. Representations concerning this proposed decision can be made to the Cabinet Member for Adults and Health via the officer contact, by the beginning of the month in which the decision is due to be taken. Cabinet on 14 January 2020 Health and Adult Services Scrutiny Committee on 15 January 2020
Background Documents (via website)	None
Author	Sarah Farragher Tel: 033 022 28403
Contact	Erica Keegan Tel: 033022 26050

A Council that works for the Community

Cabinet Member for Adults and Health

Procurement of Mortuary Services	
The Council currently has contracts with two NHS Trusts who run our Mortuary and Post-Mortem Services: • WSHT - Western Sussex Hospital Trust (covers approx. 75% of requirement) • SASH - Surrey and Sussex Health Trust (covers approx. 25% of requirement) Both contracts will expire on 22 January 2021 and there is no provision for further extensions. The Council ran a procurement in 2018/19 with a vision of having a dedicated Mortuary – 100% of bodies going into one location and moving away from traditional post-mortems towards digital non-invasive methods. However, the Council only received one bid which was subsequently deemed unaffordable. The bid was later withdrawn and the procurement process abandoned. The Cabinet Member for Adults and Health will be asked to agree the commencement of a procurement that will secure ongoing contracts for the Mortuary and Post-Mortem services from January 2021 and to delegate authority to the Director of Communities to award the contracts following the procurement exercise.	
Decision by	Mrs Jupp - Cabinet Member for Adults and Health
West Sussex Plan priority	A Council that Works for the Community
Date added	25 February 2020

Month	March 2020
Consultation/ Representations	Representations concerning this proposed decision can be made to the Cabinet Member for Adults and Health, via the officer contact.
Background Documents (via website)	None
Author	Lesley Sim Tel: 0330 022 24786
Contact	Erica Keegan Tel: 033 022 26050

Health and Adult Social Care Scrutiny Committee

11 March 2020

Self-harm and West Sussex Suicide Prevention Strategy priorities

Report by Director of Public Health

Summary

Over the five year period from 2014-15 to 2018-19, emergency admission rates for self-harm in West Sussex have been consistently higher than for England. Females aged between 15 and 29 are those most likely to be admitted. Reducing emergency admissions for self-harm is a corporate priority in the West Sussex Plan and also a priority area for action in the West Sussex Suicide Prevention Plan 2017-20.

West Sussex County Council Public Health presented on the West Sussex Suicide Prevention Plan 2017-20 at the Health & Adult Social Care Select Committee (HASC) meeting on 26 September 2019. Subsequent to the meeting both HASC and the West Sussex Suicide Prevention Steering Group have made recommendations as to additional priority areas to be addressed in the updated strategy.

Focus for scrutiny

The Health and Adult Social Care Scrutiny Committee (HASC) is asked to consider current activity to address self-harm in the county, taking into consideration the key areas of focus for scrutiny, as outlined in section 4 of the report. The Committee is also asked to consider additions to the strategic priorities of the West Sussex Suicide Prevention Strategy 2017-20 and whether these accurately reflect the views expressed by the HASC.

The Chairman will summarise the output of the debate for consideration by the Committee.

Proposal

1. Background and Context

Self-harm

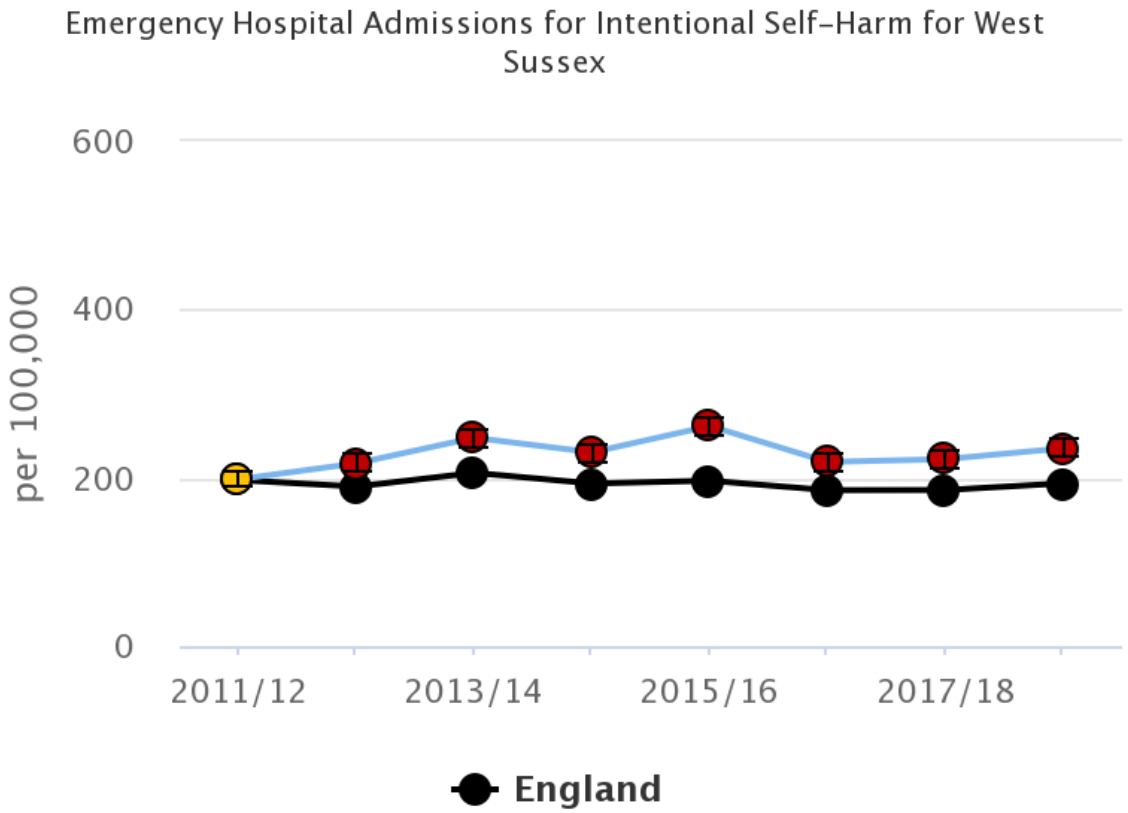
1.1 Self-harm can be defined as the act of deliberately causing harm to oneself either by causing a physical injury, by putting oneself in dangerous situations and / or self-neglect.

1.2 National Adult Psychiatric Morbidity Survey (APMS) data collected between 2000 and 2014 shows a significant increase in the prevalence of self-harm. This increase has been particularly large amongst women aged 16-24 with 1 in 5 reporting lifetime self-harm in 2014 compared to 1 in 14 in 2000. There has also

been an increase amongst males, particularly those aged 25-34, but this has been much smaller.

1.3 The reasons for this increase are unclear. It is likely that both professionals and the public have become increasingly aware and that people are more willing to report that they have self-harmed. Around 7% of female respondents to the APMS survey stated that they self-harm to cope with feelings, up from 2% in 2000. A review of research on the relationship between use of the internet and self-harm found that while online behaviour could potentially result in self-harm, there were also numerous positive aspects to internet use, including sense of community, crisis support, delivery of therapy and outreach.

1.4 In 2018-19 there were 1,845 emergency admissions for self-harm in West Sussex, a rate of 235 per 100,000 population. Females (all ages) are more likely than males (all ages) to be admitted for self-harm – 68.5% compared to 31.5% in 2017-18. The majority of female admissions were for those aged between 15 and 29. However given the levels of population prevalence detailed above, incidents of self-harm requiring an emergency admission should be considered the 'tip of the iceberg'. Also, the cohort requiring emergency admission differ from those self-harming in the community in terms of the method of self-harm; most admissions are due to self-poisoning whereas the most common method of self-harm in the community is cutting.



1.5 In terms of trends, over the five year period from 2014-15 to 2018-19 emergency admission rates in the county have been consistently higher than for England. They have not shown a significant increase or decrease. The rate of admissions for the period 2016-17 to 2018-19 has not significantly increased in

statistical terms, but there has been a numerical increase of admissions from 1,714 to 1,815.

1.6 A high rate of emergency admissions does suggest a correspondingly high prevalence in the community. However there are other factors that could impact on admissions including inappropriate referrals (e.g. educational institutions not having the necessary skills to respond to less serious incidents), a lack of access to suitable services in the community or specific drivers in the cohort for which self-poisoning is a method.

1.7 Emergency hospital admissions for intentional self-harm is a key indicator for the Strong Safe and Sustainable component of the West Sussex Plan, with a reduction in activity of 176 admissions per 100,000 population set for March 2022. Given that it significantly increases the risk of suicide, self-harm is also a priority area for action in both the West Sussex Suicide Prevention Strategy 2017-20 and the Sussex Health and Care Partnership (STP) suicide prevention workstreams. Within West Sussex County Council both the Suicide Prevention Steering Group and the LTP Emotional Wellbeing and MH Programme Board provide oversight of self-harm prevention activity.

1.8. Activity to tackle self-harm in West Sussex is taking place at a number of levels. West Sussex County Council Public Health produced a needs assessment in 2019 detailing what it knows about self-harm in the county. Subsequent to this it recruited a self-harm in educational settings lead with a focus on training. The lead has carried out a survey of educatioinal professionals and is creating a set of sustainable resources for schools including a train the trainer video, online workbooks and information on quality approved digital resources. This is part of County Council's wider programme of support around mental and emotional wellbeing in schools.

1.9 West Sussex Public Health team is convening a task and finish group to make recommendations on reducing access to medicines associated with self-poisoning and is working with stakeholders to agree a pathway to ensure appropriate support is in place for those experiencing bereavement. The team is assessing potential resource to support LGBT+ people's mental health and wellbeing.

1.9 West Sussex County Council Council and NHS partners continue to commission services at all tiers of Child and Adolescent Mental Health Services (CAMHS). There are a number of services promoting children and young people's emotional and mental health and wellbeing including Mind The Gap, Youth Emotional Support, YMCA Downslink and Find It Out Centres.

1.10 At a Sussex Health and Care Partnership (STP) level additional resource is going to be provided to support learning across the footprint including parents and to strengthen the response to people self-harming who attend A+E, but do not require specialist services. A number of priority areas have been proposed to improve crisis response for children and young people in 2020/21 as part of the STP mental health workstreams including resourcing a Crisis Home Treatment Team and delivering training to provide 111 call advisors with the skills to provide advice and guidance to young people and their families.

Suicide Prevention Strategy

1.11 At the meeting of the HASC on 26 September 2019, the Council's Public Health team presented the West Sussex Suicide Prevention Strategy 2017-20, which is due to be updated, for scrutiny. The priority areas for action in the strategy are:

- Focus on reducing suicides in vulnerable middle aged and older people, particularly those experiencing financial difficulties and social isolation
- Focus on preventing suicides in people in contact with mental health services, particularly those recently discharged or disengaged from care
- Focus on preventing suicide in people who misuse alcohol or drugs, particularly those with a dual diagnosis
- Focus on reducing self-harm, particularly in young people
- Focus on preventing suicide in people with long-term conditions or requiring end of life care, and their carers
- Improve support for people bereaved or affected by suicide
- Increase confidence and skills of paid and volunteer workers to support people at risk of suicide, maximising the use of existing resources and support
- Reduce access to the means of suicide, focusing on self-poisoning, railways and other public places
- Monitor suicide patterns and trends in West Sussex

1.12 Subsequent to the meeting, both HASC and the West Sussex Suicide Prevention Steering Group have made a number of recommendations on additional priority areas to be included in the updated stategy (all linked to SMART objectives). These are:

- People living with a dual diagnosis
- Children and young people including Children Looked After and those making a transition between Children's and Adults' Services
- Specific focus on and reference to armed forces veterans
- Increased focus on training including educational establishments, the workplace and increased community awareness of how the public can react and respond to a person who may be thinking of suicide

2. Proposal

2.1 The HASC is asked to consider current activity to address self-harm in the county to ensure that it is effectively addressing this area. The HASC is also asked to approve the additional proposed strategic priorities to be included in the updated West Sussex Suicide Prevention Strategy.

3. Resources

3.1. This paper has no additional resource implications for the Council.

Factors taken into account

4. Issues for consideration by the Select Committee

4.1 The Committee is asked to, based on the background detail of the self-harm needs assessment (Appendix A), to consider the current activity outlined in the report to address self-harm in the county. Key areas for scrutiny include:

- Based on 'what can be done' as detailed in the needs assessment, are resources focussed at the right level in terms relation to individuals, within communities and at population level;
- Work being carried out in educational settings throughout the county and planned long-term objectives;
- Potential outputs of the task and finish group considering access to medicines to reduce self poisoning;
- Short and long term work planning with partners;
- Performance monitoring i.e. West Sussex Plan indicators;
- The outcomes for West Sussex residents of work planned at Sussex-wide level.

4.2 At the meeting of the Committee on 26 September 2019, the West Sussex Suicide Prevention Strategy 2017-20, which is due to be updated, was presented for scrutiny. Subsequent to the meeting, both HASC and the West Sussex Suicide Prevention Steering Group have made a number of recommendations on additional priority areas to be included in the updated strategy, as detailed in 1.13. Members of the committee are asked to consider whether these additions to the strategic priorities accurately reflect the views expressed by the HASC.

5. Consultation

5.1 To support the activity of Self-harm in Educational Settings lead, an online survey of educational professionals has been carried out. The purpose of the survey was to assess:

- Current levels of skills and knowledge around responding to self-harm
- Additional support that could be provided to to improve the response to self-harm

6. Risk Implications and Mitigations

Risk	**Mitigating Action (in place or planned)**
Programme of activity is not effective in addressing self-harm resulting in both safety and reputational risk	Oversight of activity maintained by West Sussex Suicide Prevention Steering Group and LTP Emotional Wellbeing and MH Programme Board
Strategic priorities in updated strategy are not effectively addressed resulting in both safety and reputational risk	Oversight of strategy development and delivery maintained by West Sussex Suicide Prevention Steering Group

7. Other Options Considered

7.1 Not applicable for this report.

8. Equality Duty

8.1 Self-harm and the West Sussex Suicide Prevention Strategy impacts on people and groups with protected characteristics in several areas:

- Age and sex: Females (all ages) are more likely than males (all ages) to be admitted for self-harm. Suicide is the biggest killer of men aged 49 and under, and the leading cause of death in all people aged 20–34 years in the UK
- Sexuality: LGBT+ people are at increased risk of both self-harm and suicide
- Marital status: The process of becoming widowed (bereavement) increases the risk of self-harm and suicide.

9. Social Value

9.1 Not applicable for this report.

10. Crime and Disorder Implications

10.1 Not applicable for this report.

11. 11. Human Rights Implications

11.1 Not applicable for this report.

Anna Raleigh
Director of Public Health

Contact: Daniel MacIntyre, Acting Consultant in Public Health

Appendices:

Appendix A: West Sussex Self-harm Needs Assessment

Appendix A: West Sussex Suicide Prevention Strategy 2017-20 Priority areas and overview of key activity

Priority Area 1: Focus on reducing suicides in vulnerable middle aged and older people, particularly those experiencing financial difficulties and social isolation

- There is a comprehensive range of support for mental health and wellbeing at all tiers in the county, including:
  - The Pathfinder consortium (10 voluntary sector organisations and Sussex Partnerhship NHS Foundation Trust) provides non-clinical support, advice and signposting, engaging with 4,119 indiviudals in 2018/19.
  - Sussex Community NHS Foundation Trust's 'Time to Talk' service provides Cognitive Behavioural Therapy for people suffering from anxiety and depression as part of the national Improving Access to Psychological Therapies programme (IAPT). In Coastal West Sussex CCG and Horsham and Mid-Sussex CCG around 20% of people suffering from anxiety and depression are entering therapy which is line with the England rate. For Crawley CCG this increases to 25% which is greater than the England rate.
  - Over the next 12 months there will be a major expansion of NHS mental health crisis services in West Sussex
- The Samaritans provide emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide over the phone, in person, or via email or letter. They also provide a targeted programme of support for workplaces, schools, prisons and the military. Published national data shows that in 2018, Samaritans volunteers responded to over 3.6m calls for help by telephone, 675,757 calls for help by SMS – 17% more than in the previous year - as well as 332,411 calls for help by email, an increase of 15%. Samaritans volunteers responded to around 1,200 calls for help by letter and provided face to face support on over 30,000 occasions.
- Citizens Advice Bureau (CAB) provides advice to those experiencing financial difficulties. Social prescribing programmes providing non-clinical referral in primary care are being rolled out across the county and provide support and signposting for those experiencing financial difficulties. 51,940 cases of client assistance took place across all channels in 2017-18.
- West Sussex County Council commissions a wide range of services tackling social isolation for older people. 3,200 older people attended day activities on 65,800 occasions in in 2018-19 and 4,615 received befriending support. West Sussex adult social care also focusses on tackling social isolation as part of preventative social care.
- There are a very large number of voluntary sector activities taking place in West Sussex that bring people together. The Men in Sheds project aims to encourage social connections, friendship building and skill sharing amongst men.

Priority Area 2: Focus on preventing suicides in people in contact with mental health services, particularly those recently discharged or disengaged from care

- Suicide prevention is a key strategic priority for Sussex Partnership NHS Foundation Trust, the county's mental health trust as detailed in its Towards

Zero Suicide strategy, currently in draft form. The Trust provides follow-up activity to psychiatric patients discharged from acute hospitals within 72 hours.

Priority Area 3: Focus on preventing suicide in people who misuse alcohol or drugs, particularly those with a dual diagnosis

- Public Health commissions Change Grow Live to provide drug and alcohol treatment services in the county; there were more than 1,500 users of the service in 2018/19. The service specification explicitly states that the provider will work with other services in contact with individuals with a dual diagnosis to provide more integrated and effective care packages to achieve mutual outcomes. There are a number of homeless support services to improve access and care for homeless individuals, a group with high rates of dual diagnosis.

Priority Area 4: Focus on reducing self-harm, particularly in young people

- West Sussex Public Health Team self-harm rapid needs assessment was signed-off in August 2019. This provides a detailed analysis of activity in the county and identifies key areas for action.
- The Council has commissioned an emotional wellbeing service for schools and a self-harm lead focussing on preventing self-harm in educational settings came into post in August 2019.
- The Council and the NHS continue to commission services at all tiers of Child and Adolescent Mental Health Services (CAMHS). There are a number of services promoting children and young people's emotional and mental health and wellbeing including Mind The Gap, Youth Emotional Support, YMCA Downslink and Find It Out Centres.

Priority Area 5: Focus on preventing suicide in people with long term conditions or requiring end of life care, and their carers

- Sussex Community NHS Foundation Trust's Time to Talk Health service focusses specifically on people living with long-term conditions. The service offers phone consultations, one-to-one sessions and group work with others who experience the same symptoms. 1,170 patients have completed treatment since the services launch in May 2017.
- Promoting Compassionate Communities supporting improved end of life care is one of the four strategic priorities in the West Sussex Joint Health and Wellbeing Strategy 2019-24. West Sussex Public Health has convened a county-wide multi-agency working group to drive improvements in this area which will hold its first meeting in September 2019.
- West Sussex County Council commissions a programme of Carers'; Support. This includes the following:
  - Advice, information and support service - 60 carer support groups running each month
  - Carers assessments
  - Carer Learning and Wellbeing Programme (Modula training, 12 topics)
  - Emotional support and counselling
  - Emergency planning and support - Carers Alert Card

- Carer short break respite services (planned & emergency)
- Health and wellbeing payments
- Assistive technology/equipment for independence offer
- Specialist carer bereavement support
- Return to work/training support
- Carers Health Team

Priority Area 6: Improve support for people bereaved or affected by suicide

- Sussex Community NHS Foundation Trust Child Death Service is for families who have experienced the death of a child from age 0 up to their 18th birthday. A home visit is made initially to make an assessment of the needs of those in the family with ongoing visits from a keyworker.
- There is a range of voluntary and community sector bereavement support including: Winston's Wish offers bereavement services to families with children under 18 who have experienced a traumatic bereavement; Cruse offers support, advice and information to children, young people and adults when someone dies; Survivors of Bereavement through Suicide offers peer support throughout the county.
- West Sussex County Council Public Health Team is leading on developing an agreed bereavement pathway for the county including sudden and unexpected deaths to improve coordination of support.

Priority Area 7: Increase confidence and skills of paid and volunteer workers to support people at risk of suicide, maximising the use of existing resources and support

- Coastal West Sussex Mind provides mental health awareness training to the wider workforce and staff within primary care.
- Grassroots is a Brighton based suicide prevention charity which delivers a number of training courses and also provides resources and information
- Sussex Partnership NHS Foundation Trust has a requirement for all staff to undertake suicide awareness / prevention training
- West Sussex County Council continues to provide mental health training to employees and Private, Voluntary and Independent (PVI) service providers
- Sussex Armed Forces Network website provides online training in mental health issues affecting the armed forces and suicide prevention

Priority Area 8: Reduce access to the means of suicide, focusing on self-poisoning, railways and other public places

- Network Rail and British Transport Police continue to review incidents and make environmental modifications where necessary. For example, there have been extensive modifications at Durrington Station at which there were a number of fatalities.

Priority Area 9: Monitor suicide patterns and trends in West Sussex

- In addition to monitoring national data, there have been a number of detailed analyses of local patterns and trends. These include:
  - West Sussex Suicides Audit 2013-15

  - West Sussex Drug Deaths Audit 2015-17 (forthcoming)
  - Self-harm in West Sussex: a rapid needs analysis (2019)
- Sussex Health and Care Partnership is currently reviewing optimum way of monitoring suicide in order to identify trends and potential contagion.

Health and Adult Social Care Scrutiny Committee

11 March 2020

West Sussex Joint Dementia Strategy 2020-23

Report by Executive Director, Adults and Health

Summary

It is anticipated that in 2020 the prevalence of dementia will have reached over 16,000 people and this is expected to grow by 35% in the next 10 years with many people living with more than one long-term health condition. To be able to continue to offer a timely diagnosis and post-diagnostic support, there needs to be a focus on: how people can reduce the modifiable risks of dementia; how we can better support carers in their caring role; supporting people at risk of a crisis and how we go about targeting resources designed to keep people independent for longer and away from more expensive residential and nursing care.

The West Sussex Joint Dementia Strategy 2020-23 is the county's second dementia strategy. It builds on the progress made over the last five years in improving the experience of people with dementia, their families and carers. Setting out the Council's commitments, the Strategy provides a framework for further action to ensure the realisation of the Council's shared vision for dementia in West Sussex.

The Strategy aligns with the key priorities of the NHS Long-term Plan and West Sussex Plan around independence for later life.

Focus for scrutiny

The Health and Adult Social Care Scrutiny Committee is asked to consider the priorities set within the West Sussex Joint Dementia Strategy 2020-23 around the dementia well pathway particularly, the diagnosis and post-diagnostic stages, taking into consideration the key areas of focus for scrutiny, as outlined in section 9 of the report.

The Chairman will summarise the output of the debate for consideration by the Committee.

1. Background and Context

1.1 Dementia affects around 850,000 people in the UK and in West Sussex it is anticipated that in 2020 there will be 16,650 people living with late onset dementia which includes 500 younger people. These figures are set to rise by 35% in the next 10 years.

1.2 People with mild symptoms will normally be able to remain independent in their own home but for some people in the 'Moderate' and those in the

'Severe' categories, more support and perhaps long-term care may likely be needed.

Severity	2020	2025	2030
Mild	9,200	10,750	12,450
Moderate	5,350	6,200	7,200
Severe	2,100	2,400	2,800

1.3 There is a considerable economic cost associated with dementia with many people also living with one or more other health conditions. The County Council currently supports around 850 people over the age of 65 requiring support with their memory and cognition at an average total weekly net cost of £290,000. Much of this cost (85%) is accountable for by long-term residential and nursing care. Dementia services commissioned by the Clinical Commissioning Group cost in excess of £10m annually and the cost of emergency inpatient admissions for people with dementia is estimated to be £1.6m.

It should be noted that 68% of costs associated with dementia are for unpaid care such as the care provided by family and friend carers.

1.4 Dementia is a key priority for both NHS England and the Government. In February 2015 the Prime Minister launched his Challenge on Dementia 2020, which set out to build on the achievements of the Prime Minister's Challenge on Dementia 2012-2015.

The NHS Five Year Forward View set out a clear rationale for providing a consistent standard of support for people with dementia and their family and friend carers. Ageing well and caring for people with dementia are both key priorities in the NHS Long-term Plan and the West Sussex Plan sets out priorities around independence for later life.

1.5 In 2014, West Sussex County Council in partnership with all three Clinical Commissioning Groups (CCGs), launched its first joint strategy for dementia; the Dementia Framework West Sussex 2014-19.

1.6 A full review of the Dementia Framework took place in 2018 and findings have been used to refresh the strategy's priorities. The review was based on health and social care performance data and on findings from an extensive stakeholder engagement exercise.

1.7 The review found that there had been some progress since the launch of the Dementia Framework in 2014 with, for example, an increase in the diagnosis rate which rose from 46% in 2014 to 74.3% in 2020; an improved offer of post-diagnostic support for the individual and their family carers from Dementia Advisers and Dementia Support Workers; and the growth of dementia friendly communities, there are now 10 Local Dementia Action Alliances in the county with around 300 members committed to becoming dementia friendly businesses and organisations. There were however areas identified where little or no progress had been made and these gaps have been highlighted as priority areas within the refreshed

strategy.

1.8 The West Sussex Joint Dementia Strategy 2020-23 is West Sussex's second dementia strategy. It builds on the progress made over the last five years in improving the experience of people with dementia, their families and carers. Setting out our commitments, the strategy provides a framework for further action to ensure the realisation of our shared vision for dementia in West Sussex.

1.9 A task & finish group comprising representatives from health and social care statutory and voluntary and community sector providers have helped to drive through the development of the strategy. Alongside this, five focus groups comprising people living with dementia and/or family and friend carers from Worthing, Crawley, Horsham, East Grinstead and Chichester have helped inform and advise on the priorities.

1.10 The task & finish group identified a number of key 'gaps' in the pathway and there have been multi-agency sub-groups exploring the gaps in more detail. The sub-groups have focused on: support for people with complex and challenging behaviour; sustainable Dementia Friendly Communities; establishing a pathway to diagnosis and support for people from minority groups, people with learning disabilities and people with alcohol dependency; enabling people living with dementia and carers to access information and advice and meaningful activities and care and contingency planning.

2. Proposal

2.1 The Strategy is set around the Dementia Well Pathway which has five elements based on the themes outlined in the Prime Minister's Challenge on Dementia. They reflect the breadth of the experience of people with dementia, their families and carers from 'Preventing Well' through to 'Dying Well'. It is essential that family and friend carers are represented across the whole pathway and regard has been given to the priorities of the Joint Commitment to Carers strategy when setting our goals.

2.2 In West Sussex, there is a wide range of care and support available for people with dementia and their families and carers but this is often patchy and people often get lost trying to navigate the 'system'. We know people living with dementia face a variety of challenges and have a range of needs so to achieve our vision it is key that organisations work collaboratively. The Dementia Strategy represents the combined views of many partners, each of whom is committed to working together to make life better for people affected by dementia.

2.3 The following sections give an overview of the priorities set for each stage of the pathway and the areas of focus. A delivery plan will provide more detailed actions and measures for our ambitions in years 1,2 and 3.

3. Preventing Well

3.1 This is the first stage in the pathway and goals have been set around; reducing the modifiable risks of dementia including the need for social interaction, how we reach people at greater risk of dementia and early intervention for hearing and sight loss. Areas of focus for the strategy are those services aimed at promoting health and wellbeing and social interaction such as the social prescribing service; the Wellbeing Hubs and uptake of the NHS Health Check which can spot the early signs of dementia and provide information about the risks.

3.2 Given the evidence of a link between hearing loss, cognitive decline and dementia, early intervention and on-going support for any underlying hearing loss may have an important role to play in reducing both the risk and impact of dementia.

4. Diagnosing Well

4.1 This stage focuses on timely diagnosis and care planning and raising awareness of the early signs of dementia and the benefits of diagnosis. Areas of focus for the strategy are the diagnosis rate, the time people wait for their diagnosis, how people access information and advice and support with care planning.

- The Memory Assessment Service (MAS) continues to provide a good quality diagnosis and post-diagnostic interventions for the patient and their carer, but the ever-increasing rise in prevalence has put a strain on capacity. There will need to be continued investment into the MAS in order for it to keep up with the rising demand.
- In 2018/19, the MAS made 1,525 diagnoses of dementia, but only 3% were from people from Black, Asian and minority ethnic (BAME) groups. There needs to be an emphasis on how we reach people from hard to reach groups with information about; prevention, identification of the early signs and the positive benefits of receiving a diagnosis. A sub-group is currently exploring how we take this forward.
- For people with learning disabilities, younger people and people with alcohol related dementia, there are particular challenges around timely diagnosis because symptoms are not always picked up early enough. A sub-group has been set up to establish a more robust pathway to diagnosis and post-diagnostic support for these groups of people.
- The wait to diagnosis can often be long, this has led to people 'dropping off' the waiting list perhaps because of anxiety. We have rolled out a new Dementia Assessment Service in the south which is a one stop shop for patients which has reduced the dropout rate from 40% to 20% and worked with hospitals reducing scan times from 32 weeks to 5-8 weeks.
- This Strategy highlights the need for the individual and family carers to have a seamless route to information, advice and support during the waiting period and post-diagnosis. There will be a focus on ensuring there is a robust referral route from the MAS to providers that are able to support the person and/or their families and carers across the pathway.

- Care plans are the lynchpin of good post diagnostic support and simply having a care plan, whilst being a good start, is not enough. Any care plan needs to be personalised to the specific needs of each person with dementia and reflect changes in their care needs over time. A sub-group is looking at designing a holistic care plan that can be used by the individual, their families and carers and all those involved in the person's care throughout their journey.

5. Supporting Well

5.1 For many people dementia is not the only long-term condition they live with and they need to be enabled to manage the dementia and other conditions as much as possible for themselves, a collaborative approach across providers is key to enabling this. Areas of focus for the strategy are around enabling people to live independently for longer, a workforce skilled in dementia care, crisis prevention and the avoidance of unnecessary hospital admissions, long stays and delays to discharge.

- People need to be enabled to live at home as long as possible and housing needs to meet their changing needs. Local house planning therefore needs to reflect the growing need and the rise in prevalence across the county. Housing providers can also play a key role by supporting Dementia Friendly Communities and ensuring their staff are dementia aware. They can help identify the symptoms of dementia and encourage them to seek support.
- There also needs to be a clear offer of equipment and assistive technology that optimises the individual's wellbeing and independence and support for the carer.
- People with greater needs, may require more support and it is important there is a workforce across the dementia care system that has the right skills, behaviours and values to provide compassionate, culturally sensitive, person-centred care. It is therefore important all providers have a framework for dementia training in place that ensures staff receive training relevant to their role.
- Contributory factors to a crisis such as carer breakdown, physical health problems or social factors related to the person with dementia or their environment need to be identified by health and social care providers early on and interventions provided where necessary. Contingency planning with the individual and their families and carers should take place early as possible in the person's journey.
- People with dementia are at greater risk of an unnecessary hospital admission usually because of falls, urinary track infections (UTI's) etc. Stays in hospital are often longer and there can be delays in discharge often because of the time taken to arrange packages of care. Health, social care and community and voluntary sector providers need to work together to provide a joined-up approach to supporting the person at risk of an unplanned hospital admission or delayed discharge and tools such as 'Knowing Me' that provide key information for hospital staff about their patients need to be utilized.

6. Living Well

6.1 There is potential for people with dementia to live meaningful and satisfying lives, but this requires support from all those people and services surrounding the person including their own community. Areas of focus for the strategy are around; the need for safe, accessible and welcoming communities, supporting family and friend carers, and access to information and advice and meaningful activities.

- Dementia Friendly Communities can help break down the stigma of the condition and allow people affected by dementia to access their community. Everyone can help to make their communities more dementia friendly and public sector organisations such as the County Council and the CCG have a particular role to play in ensuring all staff are skilled in dementia care at a level relevant to their role.
- Local Dementia Action Alliances (LDAAs) help enable Dementia Friendly Communities and these have grown considerably in the past five years with a membership of around 300 members including local businesses, community groups, faith groups, schools and colleges, libraries, museums, shopping centres and charities as well as health and social care providers. There continues to be concern over how this work can be sustained and a coordinated response to how LDAAs are supported and funded going forward is required. A sub-group is currently looking at what can be achieved within current resources and with a little funding.
- Caring for someone with dementia can put a huge strain on the carer's physical and mental health and finances. The carer needs access to information and advice, support and respite so that they can continue in their caring role together with a coordinated offer of training. Carers can also become cut off from the community leading to social isolation and resultant worsening of health. There needs to be a consistent offer of peer support, carers groups, and support to find and maintain paid and unpaid work that help them to stay connected.
- For people living with dementia there should be the offer of a range of affordable activities that are tailored to their individual needs and consideration should be given to ensuring activities are inclusive of people from diverse groups. People also need support to be able to take part in non-specialist/mainstream groups and activities or paid and unpaid work.
- Travelling to groups and activities can be challenging particularly as many people with dementia are no longer able to drive. There needs to be a robust transport plan in place and more local based provision.
- Access to information and advice about living with dementia, welfare benefits and the support available is key to ensuring all people affected by dementia can continue to live well with the condition. There needs to be a 'no wrong door' approach to the level and quality of information people can access which calls for better sharing of information.

7. Dying Well

7.1 Areas of focus for this stage of the pathway are around; ensuring people receive good person-centred compassionate care by skilled staff at the end

of their life, people being enabled to die in the place of their choosing, supporting families and carers at end of life and bereavement support and counselling.

- People should have the opportunity to plan for their end of life care along with those around them, as soon after diagnosis as possible. This reduces the likelihood that difficult and emotional decisions have to be made in crisis when the wishes of the person with dementia cannot be taken into account. Where consent is given, the plan should be shared with all those involved in the person's care.
- People nearing the end of their life need to receive coordinated, compassionate care that is individual to their needs. This includes palliative care for the person with dementia and bereavement support for carers. Care needs to be delivered by skilled staff throughout the person's life journey. Hospices can play an important role in supporting staff to care for people with dementia, as well as caring directly for people with dementia especially where the person has more than one long term condition.
- Care for one another in times of grief and loss is everyone's responsibility and supportive networks have a key role in supporting people during illness, dying and bereavement. This ambition links in with Public Health's work around Compassionate Communities.

7.2 Dementia prevalence continues to rise in line with the ageing population and it will be necessary to ensure there is continued investment in services designed to provide a timely diagnosis and ongoing care and support to ensure they keep up with the rise in demand. We also need to; enable people to reduce the modifiable risks of dementia, redesign and transform services to focus resources on keeping people independent for longer, support family and friend carers in their caring role and support a community-led approach to enabling people to live well with dementia. A delivery plan underpins this Strategy which includes objectives that can be achieved with current resources and a set of more ambitious targets that can be achieved with a little or much more funding.

7.3 We know that to really meet the needs of the individual, it is important to listen to them. We will therefore involve people living with dementia and their families in helping us achieve the aspirations set out in this Strategy and will continue to re-visit our vision to ensure the voice of lived experience not only remains central to the strategy but helps to measure the impact of it.

8. Resources

8.1 There is currently no additional funding identified for the implementation of the new Dementia Strategy. The sub-groups mentioned in this report have looked at what can be achieved with current resources and what can be achieved if there is a little or a lot more funding available in the future. These aspirations together with some estimated costings have been included with the delivery plan to be used as a basis for any future business case.

9. Factors taken into account

9.1 Issues for consideration by the Select Committee

9.2 The Committee is asked to consider the priorities within the West Sussex Joint Dementia Strategy 2020-23 around the dementia well pathway particularly the diagnosis and post-diagnostic stages. Key areas for scrutiny include:

- Plans to address priorities where little progress has been made in the previous strategy;
- Plans to address the gaps in the current dementia pathway;
- Areas of focus in relation to prevention activities;
- Diagnosis rates and future plans for the Dementia Assessment Service;
- How the consultation findings have informed the updated strategy;
- The deliverability of the high-level delivery plan;
- Plans for ongoing performance monitoring.

10. Consultation

10.1 An extensive stakeholder engagement took place in 2018 as part of the review of the Dementia Framework 2014-19. This comprised focus groups and interviews with people living with dementia, family and friend carers and health and social care staff; two on-line surveys for residents and health and social care staff through the "Have Your Say" online portal. In total 366 people took part in the engagement.

10.2 Focus groups comprising people living with dementia and family and friend carers have been consulted in the development of the new Strategy along with carers groups and the Sangam Women's group, an association of Asian women.

10.3 A multi-agency task & finish group comprising representatives from health, social care, district & borough councils and community and voluntary sector providers have helped drive the Strategy through. The strategy has been further shared with Local Dementia Action Alliances and internal and external partners.

10.4 The Strategy has been presented to the Health & Wellbeing Board, Adults & Health Leadership team, Clinical Commissioning Group's Quality Committees and LMT.

11. Risk Implications & Mitigations

Risk	Mitigation Action (in place or planned)
Strategic priorities identified in strategy are not implemented resulting in both poor outcomes and reputational risk	A Dementia Strategic Partnership Board will be established that will monitor the progress of this Strategy, identify gaps and work together to help find solutions
Strategy does not address emerging issues	Review of the Strategy in 2023

12. Other options considered

12.1 Not applicable for this report.

13. Equality Duty

13.1 The strategy impacts on people and groups with protected characteristics in several areas:

- Age: Although dementia can affect people of any age it is more common in people over the age of 65.
- Ethnicity: People from BAME groups are at an increased risk of dementia, but among this population there are lower levels of awareness of dementia and high levels of stigma associated with the condition. People from BAME backgrounds are under-represented in dementia services and tend to present to services later.
- Learning disabilities: People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s.
- Sexuality: People from LGBT+ community are less likely to have family members and children to provide support. They are also more likely to live on their own and be single. Many LGBT+ people fear that mainstream care services will not be willing or are not able to understand how to meet their needs.

14. Social value

14.1 Not applicable for this report.

15. Crime and disorder implications

15.1 Not applicable for this report.

16. Human rights implications

16.1 Not applicable for this report.

Kim Curry, Executive Director, Adults and Health

Contact: Irene Loft, Senior Commissioning Officer, Adults & Health Directorate, 033 022 23793 email: irene.loft@westsussex.gov.uk

Appendices:

Appendix A: West Sussex Joint Dementia Strategy 2020-23
Appendix B: Dementia Cartogram
Appendix C: High level delivery plan

Background Papers - None

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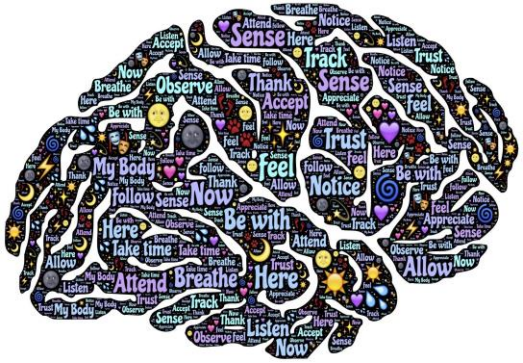


WEST SUSSEX
JOINT DEMENTIA STRATEGY
2020 TO 2023

Developed in partnership with
West Sussex County Council and
NHS Clinical Commissioning Group

CONTENTS

ACKNOWLEDGMENTS

We are very grateful to the residents of West Sussex, our partners, staff and other stakeholders who were instrumental in the successful development of this strategy through their participation and feedback.

Particular thanks go to Alzheimer's Society's Chichester & Bognor Positive Thinkers, Horsham Rusty Brains and Worthing Town Cryers, Age UK West Sussex Cando@K2, Sangam Women's Group and Carers Support West Sussex East Grinstead carers group.

FOREWORD

With the ageing population of the county expected to rise exponentially in the next 10 years, a timely diagnosis for those with dementia is vital not only for them, but also for their family and friends. A timely diagnosis enables them to maximise control over their lives by planning ahead and accessing support to ensure that they can enjoy an active and independent life for as long as possible.

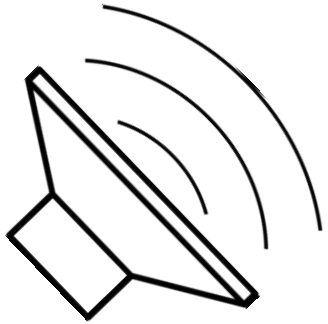
The County Council and the NHS Clinical Commissioning Group are resolved to make West Sussex the best place to live well with dementia. This strategy sets out how we aim to do this and how we can provide the help and support that is needed in order to realise this aim. From prevention to diagnosis and to delivery of services, we must ensure that there is adequate and meaningful provision to help and support those with dementia, as well as their family and friends.

Promoting self-care and self-empowerment is often a primary requirement for those who want to stay in their own homes. Family and friend carers are influential in supporting those living with dementia and it is therefore key that we support them in their caring role. Carers tell us that their wellbeing is as much about their experience of the health and social care system as it is about services for them. We need the system not only to recognise carers, but to listen to them and involve them as appropriate.

I hope you will find this strategy informative and of interest. I believe that the more we engage and plan together with those who need our support, the better quality of life will be achieved for them which for me is of paramount importance.

Amanda Jupp

Chair – West Sussex Health and Wellbeing Board Cabinet Member for Adults and Health West Sussex County Council



INTRODUCTION

This is West Sussex's second dementia strategy. It builds on the progress made over the last five years in improving the experience of people with dementia, their families and carers. Setting out our commitments, the strategy provides a framework for further action to ensure the realisation of our shared vision for dementia in West Sussex.

This strategy has been developed in partnership with Health, Social Care, Councils and Community and Voluntary providers. It is based on the findings of the 2018 review of the Dementia Framework West Sussex 2014-19 and includes direct input from people with dementia and their families and carers. The Strategy sits within the context of national and local policies, guidance and legislation.

It was identified though that there is still more that needs to be done to improve the experience of people affected by dementia. This Strategy sets out how we plan to build on the progress that has been made and address the gaps.

This new Strategy refreshes our goals so that they better reflect the current financial climate, the changing needs of the population together with new local and national plans and guidance, policies and legislation. The Strategy aims to set out the plan for action over the next three years by the County Council and the Clinical Commissioning Group (CCG) in order to inform the planning, commissioning and provision of services.

This Strategy is not a stand-alone document but sets the direction of travel and complements the many strategies and plans we already have, under one clear vision and purpose.

What is dementia?

The term dementia describes a set of symptoms including memory loss, mood changes, and problems with communications and reasoning. It is caused by diseases of the brain, the most common being Alzheimer's.

Dementia is not a natural part of growing old and, although dementia is more common in people over the age of 65, the condition can also be found in younger people.

Purpose of the Strategy

Findings from a review of the current Dementia Strategy, the Dementia Framework 2014-19 in 2018, showed there had been improvement.
In 2014 the diagnosis rate for West Sussex was just 46%, this has risen and is now around 66%; there has been an improved offer of post-diagnostic support for the individual and their family carers from Dementia Advisers, Dementia Support Workers, carer support services. Our communities have become more dementia friendly places to live and there are now 10 Local Dementia Friendly Community Groups with 300 members committed to becoming dementia friendly businesses and organisations.

How we will get there

- There needs to be a collaborative approach across health, social care, community, voluntary and private providers, together with local people to achieve our objectives.
- A focus on community-led support is necessary to achieve our ambitions together with a willingness to innovation and learning.
- People living with dementia need to be enabled to live independently for as long as possible and supported to see the value they bring and resources around them rather than focusing on any negative characteristics.
- The strategy will be supported by a delivery plan with clear measures and points of review to ensure that the intended aims are being achieved. The delivery plan includes a set of objectives across the pathway that looks at how we can work more collaboratively as partners to ensure best value is achieved in commissioned services within the current resources. The delivery plan also includes a separate set of more ambitious targets which can be used for making the case for any additional funding should this become available in the future.

Audience for the strategy

The primary audience for the West Sussex Joint Dementia Strategy 2020-23 is the Health & Wellbeing Board, local leaders, officers, commissioners and providers responsible for its delivery. However, care has been taken to make the strategy as accessible as possible for residents, staff and partners in understanding priorities and how all partners can contribute to them.

UNDERSTANDING THE CHALLENGE

There are four main challenges we must address over the course of this strategy.

1. **An ageing population**. The prevalence of dementia is set to rise exponentially over the next ten years with people often having other significant and life-limiting chronic conditions. This will place a huge demand on capacity within services.

2. **Timely diagnosis and support.** There can be long waits to diagnosis and there are particular issues for younger people, people with learning disabilities and people from black, ethnic and minority groups.

3. **A consistent offer of information and advice and support.** Information and advice and support is normally provided at diagnosis but people need to be able to access support and coordinated information and advice **at every stage in their journey**.

4. **Challenges within the care market**. These are around recruiting and retaining health and social care staff skilled in delivering good quality dementia care and reductions in the number of care home beds registered to support people with dementia.

STRATEGY DEVELOPMENT PROCESS

Review of the Dementia Framework West Sussex 2014-19 including engagement with wider stakeholders.

- Identification of key issues and emerging themes
- Multi-agency task & finish group to drive strategy
- Engagement with people with lived experience
- Themed sub groups
- Draft strategy consultation with stakeholders
- Strategy update and sign-off

OUR VISION

To improve the health and wellbeing of local people, and for those people who develop dementia to be supported to maintain their independence for as long as possible and enjoy a good quality of life for as long as possible.

People with dementia and their families and carers receive high quality, compassionate care and support, with timely diagnosis and access to good information and advice.

People with dementia and family and friend carers have access to timely, skilled and well-coordinated support throughout their journey.

People with dementia and their family and friend carers receive care and support that focuses on an individual's strengths and looks to promote their wellbeing.

People with dementia, along with their families and carers are central to any processes or decision making, and wherever possible are helped to express their own needs and priorities.

For supportive communities, where people feel able to participate in community life without stigma.

WHERE WE ARE NOW

In 2018, a full review of the Dementia Framework West Sussex 2014-19 took place. It was led by the County Council and all three Clinical Commissioning Groups and included a public engagement with around 400 different people and organisations. These are just a few of the achievements that were identified as part of the review:

West Sussex Dementia Learning & Development Framework. An on-line resource to signpost people to free learning resources.

All hospital staff trained in dementia awareness, care and support. John's Campaign and open visiting hours are just a few of the initiatives taking place in all our hospitals to improve patient outcomes.

Dementia Zone on the Council's Connect To Support website providing information about dementia and links to support.

Learning and training for family and friend carers through Alzheimer's Society and Carers Support West Sussex.

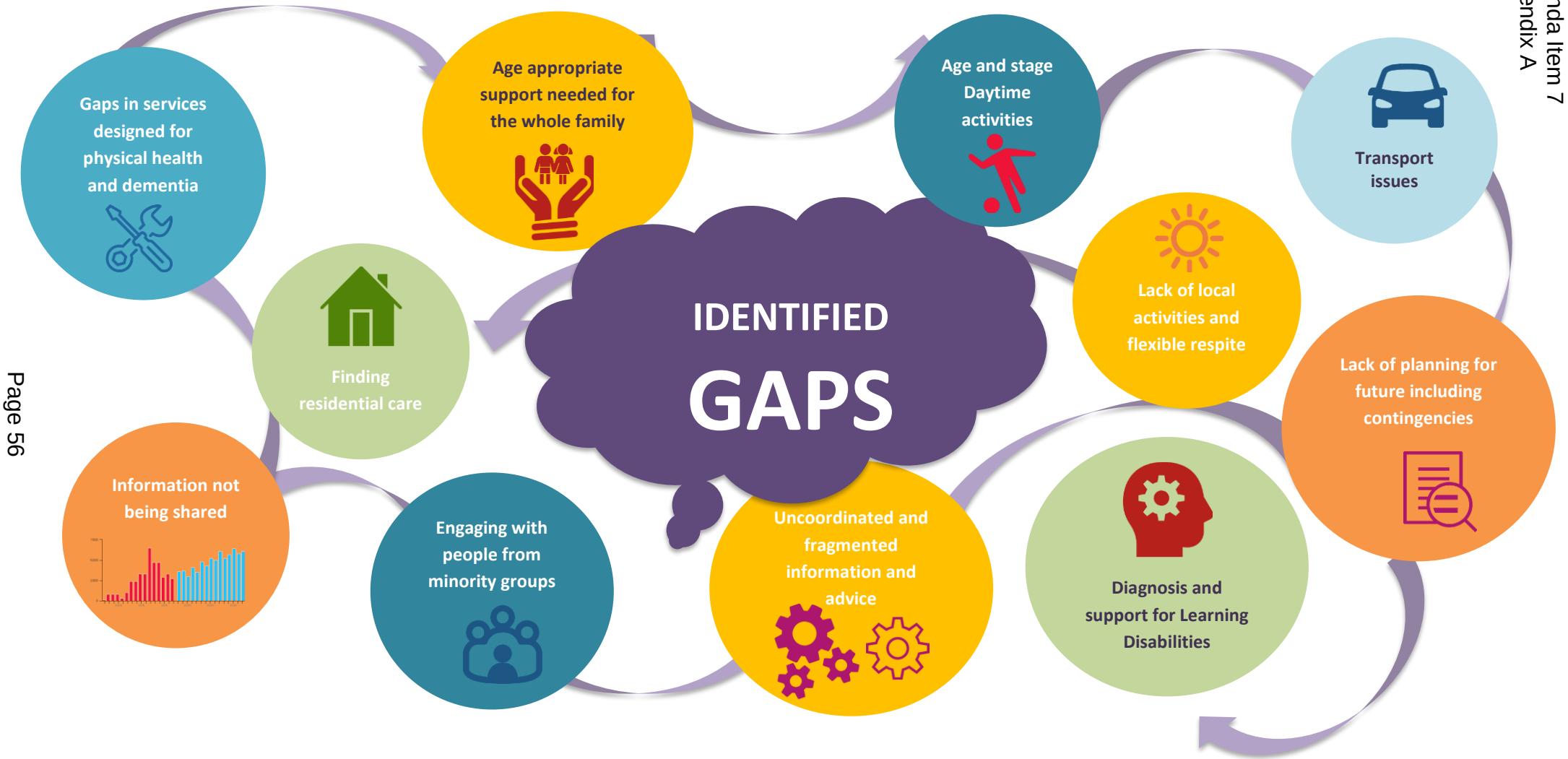
More people receiving a diagnosis and follow-up support. Around 20% more people are now receiving a diagnosis of dementia and the number of people registered with GP's has increased by 28%.

A more dementia-friendly West Sussex. 10 Local Dementia Friendly Community Groups in West Sussex and around 300 members.

Libraries running Memory Management Ticket; Reminiscence Collections, dementia awareness drop-ins and Reading Well Books on Prescription for dementia.

Weekend away short breaks for younger people living with dementia run twice a year.

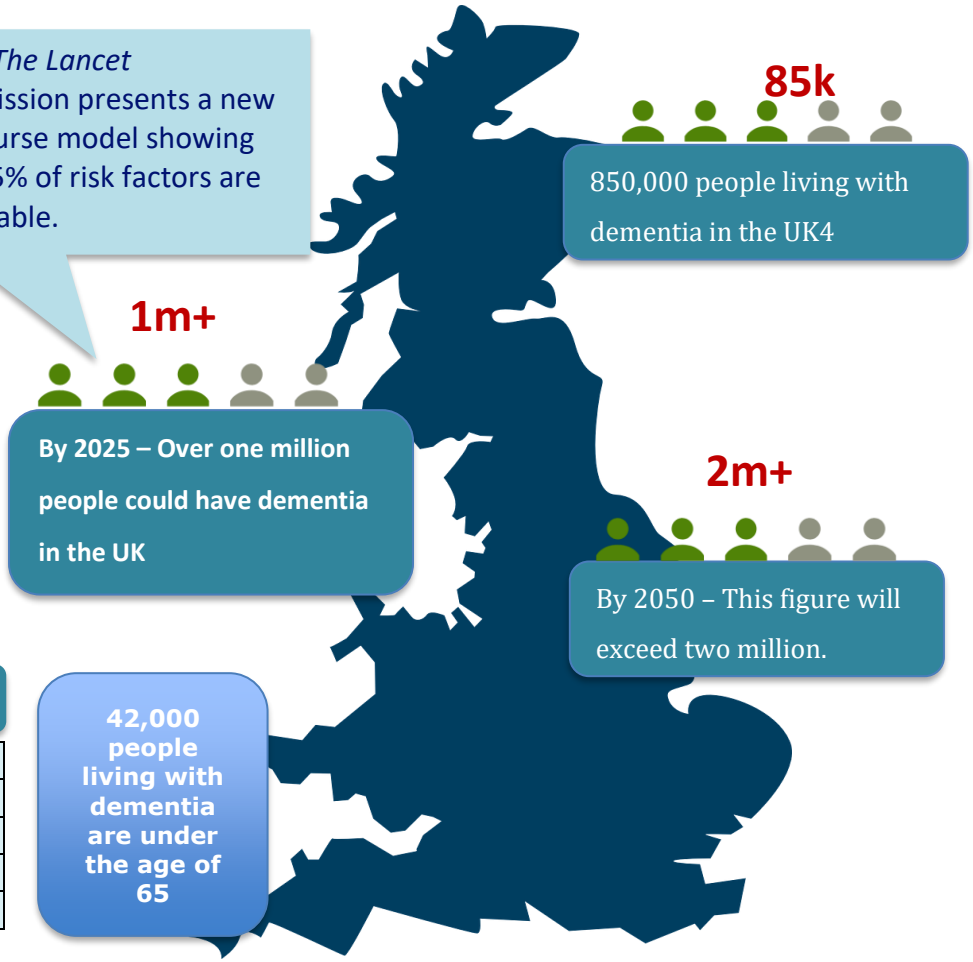
However, there is a significant number of people living in West Sussex with undiagnosed dementia and many people who feel unsupported following diagnosis. This document sets out what we plan to do about this.


IDENTIFIED
GAPS
Gaps in services designed for physical health and dementia
Age appropriate support needed for the whole family
Age and stage Daytime activities
Transport issues
Finding residential care
Lack of local activities and flexible respite
Lack of planning for future including contingencies
Information not being shared
Engaging with people from minority groups
Uncoordinated and fragmented information and advice
Diagnosis and support for Learning Disabilities

THE NATIONAL PICTURE

Most people associate dementia with older people but there are more than **40,000 people in the UK under the age of 65** years who are affected by this condition.

Note: The Lancet Commission presents a new life-course model showing that 35% of risk factors are modifiable.



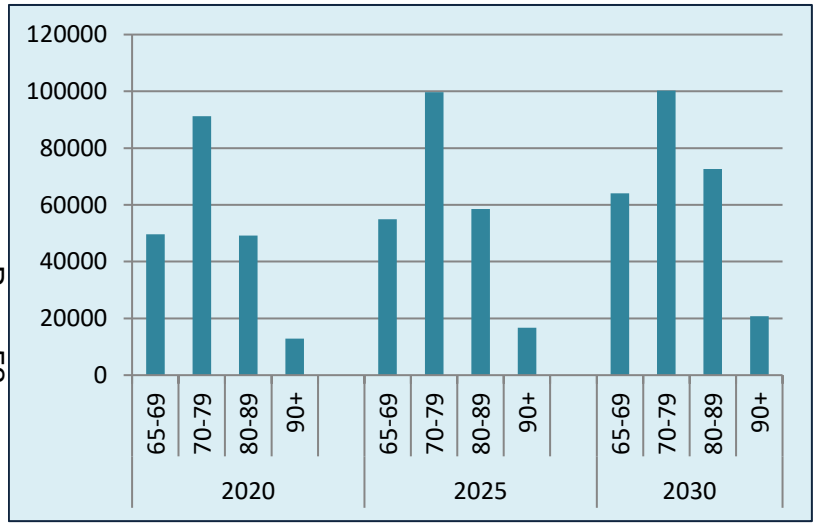
Projected number of older people living with dementia 2019-2040 England

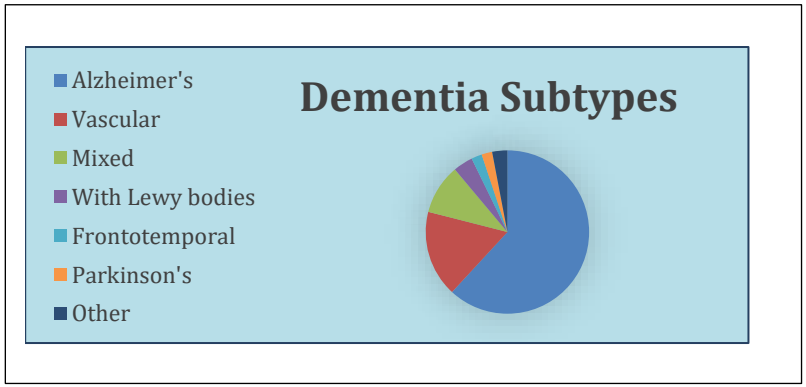
	2019	2020	2025	2030	2040	%change
Mild dementia	107,100	108,300	118,900	136,100	166,700	56%
Moderate dementia	206,300	198,900	210,100	235,600	276,100	34%
Severe dementia	434,600	461,900	569,400	674,400	909,600	109%
Total	748,000	769,200	898,500	1,046,100	1,352,400	81%

Many people with dementia also live with one or more other health conditions. Studies have shown that: 41 per cent have high blood pressure • 32 per cent have depression • 27 per cent have heart disease • 18 per cent have had a stroke or transient ischemic attack (mini stroke) • 13 per cent have diabetes (Barnett et al, 2012).[1]

THE LOCAL PICTURE

The population of people over age 65 is set to rise in the next 10 years





Highest increase is in people aged over 80

See Appendix C for a cartogram showing estimated population over age 65 with dementia at ward level

How dementia might look in next 10 years

	2020	2025	2030
Early onset (under 65)	500	550	600
Late onset	15,700	18,250	21,300
Total dementia	**16,650**	**19,350**	**22,450**

Severity	2020	2025	2030
Mild	9,200	10,750	12,450
Moderate	5,350	6,200	7,200
Severe	2,100	2,400	2,800
TOTALS	**16,650**	**19,350**	**22,450**

People with mild symptoms will be able to remain independent in their own home. For some people in the 'Moderate' and those in the 'Severe' categories, more support and perhaps long-term care may likely be needed.

No. People with Down's Syndrome in West Sussex likely to have dementia

Age in Years	2009	2015	2020	2025	2030
45 -54	9	10	10	10	8
55-64	18	18	18	21	21
Sub-Total: 35 - 64	**27**	**28**	**28**	**31**	**29**
65 and over	1	2	2	2	2
TOTAL	**28**	**30**	**30**	**33**	**31**

Source: www.pansi.org.uk/index and www.poppi.org.uk/index

This strategy is based on the following relevant national and local policy, guidance and legislation:

NATIONAL CONTEXT

The **NHS Five Year Forward View** and the Department of Health **Prime Minister's challenge on Dementia 2020** set out a clear rationale for providing a consistent standard of support for people with dementia and their family and friend carers.

Ageing well and caring for people with dementia are both key priorities in the **NHS Long Term Plan**. The Plan focuses on the need for people to be helped to stay well and to manage their own health guided by digital tools. It also calls for a transformed workforce with a more varied and richer skill mix.

Care Act 2014 created a new legislative framework for Adult Social Care. Local Authorities have new functions to ensure people who live in their areas receive services that prevent their care needs from becoming more serious or delay the impact of their needs and to have a range of provision of high quality, appropriate services to choose from. The Care Act also gave carers a legal right to assessment and support.

Five Dementia 'We' Statements published in 2017 by the National Dementia Action Alliance. They reflect what people with dementia and carers say are essential to their quality of life. (See Appendix A)

LOCAL CONTEXT

West Sussex Plan – Priorities around Independence for Later Life.

Sussex Health and Care Partnership Strategic Delivery Plan – **Appendix -** West Sussex Place Based Response to the Long-Term Plan October 2019

Joint Commitment to carers 2015-20 – states the main priority areas for family and friend carers for health and social care. This document will be refreshed during the course of this Strategy.

West Sussex Joint Health & Wellbeing Strategy 2019-24 sets out the Health and Wellbeing Board's vision, goals and ways in which it will work to improve the health and wellbeing for all residents in West Sussex.

Adult Social Care in West Sussex – Our vision and strategy 2019-21 - sets out how we will continue to work together to build on the good progress we have made to implement a strength-based community-led approach, focusing on prevention and reablement, supporting family and friend carers, and working towards the integration of services. It is anticipated this document will be refreshed during the course of this Strategy.

Sussex Community NHS Foundation Trust Dementia Strategy.

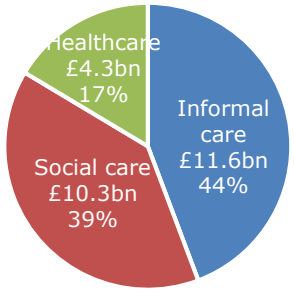
Western Sussex Hospitals NHS Trust Dementia Strategy

THE ECONOMIC COST

The number of people with dementia is set to rise exponentially over the next ten years with many people also living with one or more other health conditions. There is a considerable economic cost associated with dementia and this will place a huge demand on capacity within services where there has already been a reduction in public funding.

In the UK the majority of dementia costs per year are due to informal care, social care and healthcare costs. Total cost is over £26bn[10].

Social care is projected to account for a slightly larger proportion of the total costs, and unpaid care a slightly lower proportion, in 2030 than in 2019. The proportion of older people living with dementia who have severe dementia is projected to rise in the next decade (see 'Local Picture' section). The likelihood of living in a care home increases with severity of dementia, which means that this rise will impact on the cost of social care over time.



West Sussex Projected costs of dementia by type of care (in £million, 2015 prices)[9]					
	2019	2020	2025	2030	%growth
West Sussex	618	653	827	1068	73%
Healthcare	83	86	107	136	64%
Social care	299	321	412	535	79%
Unpaid care	232	242	304	390	68%
Other	3	4	5	7	124%

The total costs here include all those associated with supporting older people living with dementia rather than the extra costs attributable specifically to dementia itself.

Around a third of projected costs of dementia are saved through the care of family and friend carers (ie unpaid care). This is set to rise by 68% over next 10 years.

The County Council currently support around 850 people over the age of 65 requiring support with their memory and cognition at an average total weekly net cost of £290,000. Much of this cost (85%) is accountable for by long term residential and nursing care.

More than half the number of people in this group are over the age of 85 with a total weekly net spend on residential and nursing care of around £128,000. With numbers of people in this age group expected to rise by 60% in the next 10 years, resources will need to focus on keeping people at home for longer and away from more expensive long-term care.

Dementia services commissioned by the Clinical Commissioning Group cost in excess of £10m annually and the cost of emergency inpatient admissions for people with dementia is estimated to be £1.6m*.

The need to ensure we continue to improve services to meet the needs of people affected by dementia is a high priority. However, the County Council and Clinical Commissioning Group are working with reduced public funding. It will be necessary to ensure there is continued investment in the services designed to provide a timely diagnosis and ongoing care and support to ensure they can grow in line with the rise in demand. It is also important to continue to look at how we can: enable people to reduce the modifiable risks of dementia; redesign and transform services to focus resources on keeping people independent for longer; support family and friend carers in their caring role and support a community-led approach to enabling people to live well with dementia.

A delivery plan underpins this strategy and includes a set of objectives across the pathway that looks at how we can work more collaboratively as partners to ensure best value is achieved within current resources. The delivery plan also includes a separate set of more ambitious targets which can be used for making the case for any additional funding should this become available over the course of the Strategy.

*People aged 65+ with dementia that are short stays (1 night or less) is estimated to be £1.6m. 2017 data

THE DEMENTIA WELL PATHWAY

The Dementia Well Pathway has five elements based on the themes outlined in the Prime Minister's Challenge on Dementia. They reflect the breadth of the experience of people with dementia, their families and cares from prevention to end of life care. This strategy has used the dementia well Pathway as a framework with which to present its goals for the next three years.

FAMILY AND FRIEND CARERS

It is essential that family and friend carers are central across the pathway. In line with the Joint Commitment to Carers this Strategy will ensure:

- Carers are identified and supported as early as possible.
- Carers are considered partners in the care of the person with dementia.
- Carers are offered an assessment of their need and support that is individual to them.
- Carers have good access to information and advice about dementia in a format that is right for them from the time before diagnosis all the way through to the end of life stage and bereavement.
- Carers are supported to stay physically and mentally well and have access to psychological therapies.
- Carers have regular breaks from their caring role and given the opportunity to pursue interests individual to them as well as accessing or maintaining paid or unpaid work.
- Carers are offered one-to-one support and provided with opportunities to meet other family and friend carers.

PREVENTING WELL

West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that there is greater awareness of the preventable and modifiable risk factors for dementia and that people have the necessary support to reduce their risks for themselves.

Overview

More people in West Sussex are living for longer, many not in good health and spend years living with complex and long-term health and care needs such as dementia. This puts extra demand on health and care services and makes it more difficult for patients to receive the right level of care. There are some risk factors you cannot change but research suggests up to one in three cases of dementia are preventable. Risk factors that may be preventable include:
Diabetes (type 2) high alcohol intake - high blood pressure - lack of exercise - obesity - poor physical health - smoking.
Other risk factors that could contribute to the risks are: hearing loss, depression and social isolation.

The are many services, groups and activities working to help reduce the risk factors associated with dementia but there needs to be a whole systems approach to this. A whole system approach works with communities and stakeholders to both understand the problem and to support identification and testing of solutions.

For many people, there is a lack of understanding about the risks of dementia and this is particularly so for people with learning disabilities or those from Black and Minority Ethnic (BAME) groups who are at an increased risk. Greater awareness raising needs to take place about the modifiable risks through communications, community events, health checks etc.

Key Issues & Challenges

- Communicating good quality information about risk factors, early signs of dementia and the benefits of diagnosis across the population but particularly for people from hard to reach groups including black and minority ethnic (BAME) communities where there is an increased risk of dementia and the diagnosis rate has been historically low.
- Risk factors that may contribute to dementia across the life course such as educational attainment, physical inactivity etc. as identified in the Joint Health & Wellbeing Strategy.
- For people with learning disabilities, particularly Down's Syndrome, where there is an increased risk of dementia, there is a need to ensure that they and their families and carers have access to information, in an accessible format, at an early stage about the risks of dementia and the early signs.

Prioritising prevention
The recent government policy document 'Prevention is better than cure' (2018) sets out a call to action for prevention to be at the heart of everything we do. This is reiterated by the NHS Long Term Plan (2019) positive shift towards prevention and reducing health inequalities. The Plan also emphasises the need to make better use of Digital Technology.

Our goals	What we mean
People live, work and play in environments that promote health and wellbeing and support them to live healthy lives.	• Reduction in people who are overweight or obese. • People are aware of the impact that their alcohol consumption and smoking is having on their long-term health. • People are more physically active. • People with learning disabilities receive regular Annual Health Checks. • Greater awareness of the preventable risks of dementia across the life course i.e. younger people and people in mid life. • Good access to green spaces, leisure centres etc.
Individuals, families, friends and communities are connected.	• To work with our communities and partners to empower and support networks of families, friends and communities to find solutions to local problems which have an impact on dementia risk. *(West Sussex Joint Health & Wellbeing strategy 2019-24)*
There is greater awareness and understanding of the factors that increase the risk of dementia and how people can reduce their risk by living a healthier life	• For people to have access to information and advice so that they understand the risk factors for dementia and how their risk could be reduced. • Greater awareness of the risk factors of dementia across the life course such as educational attainment, physical inactivity etc. as identified in the Joint Health & Wellbeing Strategy. • Carers are supported to remain physically and mentally well (West Sussex Joint Commitment to Carers 2015-20) There is greater public awareness about dementia and increased understanding to reduce stigma. • All groups of people including those from black and minority ethnic (BAME) communities, religious minority communities and Gypsy and Traveller communities as well as people with learning disabilities are aware of the symptoms of dementia and know what steps they can take to reduce their risks. • People accessing behaviour change interventions and programmes in mid-life are advised that the risk of developing dementia can also be reduced. • Adults aged 40 to 74 access the free NHS Health Check that is designed to spot early signs of heart disease, diabetes, kidney disease, stroke and dementia. An NHS Health Check also help find ways to lower the risk and provides information on dementia risk reduction.
Early intervention and ongoing support for hearing and sight loss	• Given the evidence of a link between hearing loss, cognitive decline and dementia, early intervention and on-going support for any underlying hearing loss may have an important role to play in reducing both the risk and impact of dementia. National Institute for Health & Care Excellent (NICE) recommends that local services consider: referring adults with diagnosed or suspected dementia or mild cognitive impairment to an audiology service for a hearing assessment and referring adults with diagnosed dementia or mild cognitive impairment to an audiology service for a hearing assessment every 2 years if they have not previously been diagnosed with hearing loss. • There should be greater awareness of the need to receive regular sight tests and hearing tests.

PREVENTING WELL

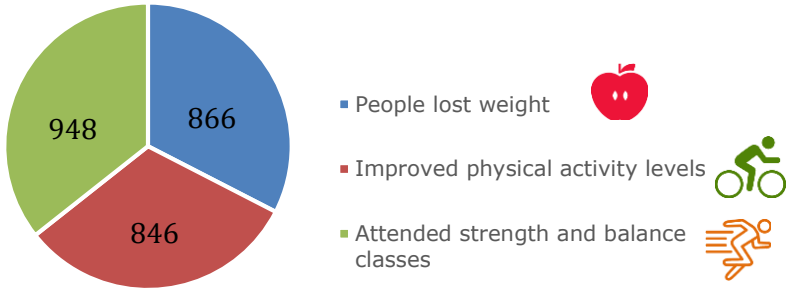
Examples of Local Key Initiatives**

- Social prescribing service being run out of a number of West Sussex GP surgeries. Social prescribing involves empowering individuals to improve their health and wellbeing and social welfare by connecting them to non-medical and community support services.
- West Sussex Wellbeing hubs coordinate services that can help improve a person's health and wellbeing. There are local teams that can give advice and support on how to make small changes to improve health and wellbeing, such as how to stop smoking, how to become more active or how to make meals healthier. Wellbeing is a friendly and impartial service. Most of the services are free or at very low cost.
- NHS Health Check is a national programme in England for people between the ages of 40 and 74. It is a free 30 minute check to assess the risk of developing heart disease, stroke, diabetes and kidney disease. An NHS Health Check also helps find ways to lower the risk and provides information on dementia risk reduction.
- Thriving Connections is sponsored by Adur & Worthing Councils, the County Council and the Clinical Commissioning Group. This is a project focusing on ways that loneliness and social isolation might be tackled in a more innovative way.
- Make Every Contact Count (MECC) – an initiative aimed at providing the knowledge and skills to enable public facing workforces to deliver very brief interventions on health and wellbeing.

**commissioned and non-commissioned services

KEY DATA

In 2017/18 948 adults were supported through the Wellbeing Hubs.



In 2017/18:

68% of adults physically inactive

62% adults classified as overweight or obese

13% of adults were smokers

20–40% of people with dementia will have depression.[11] Depression is more common in people with dementia than those without. Depression is also common among family carers

In 2018-19 35.5% of those eligible took up the offer of an NHS Health Check

41%* of adult social care service users who have as much social contact as they would like.

35%* of adult carers having as much social contact as they would like.
*2017/18

DIAGNOSING WELL

> *West Sussex County Council and the Clinical Commissioning Group want to see all groups of people diagnosed earlier and get timely access to good quality post-diagnostic support. With a named coordinator and support to plan their future care along with those people important to them.*

Overview

- For many people a diagnosis of dementia, like many other illnesses, can be traumatic but for many people it can also come as a relief. It helps people to plan ahead while they are still able to make important decisions. A timely diagnosis and follow-up support enable people with dementia and their family and friends the ability to maximize control over their lives and help to ensure that they can manage their condition, with the aim of ensuring they can live independently for longer.
- In West Sussex, the pathway to diagnosis is normally through the GP who will refer the patient to the Dementia Assessment Service (DAS) or the Memory Assessment Service (MAS) once all other reversible causes of cognitive decline are ruled out. The MAS/DAS provides a high-quality diagnosis and follow up support for the patient and their family and friend carer from a Dementia Adviser.
- There can often be a long wait to diagnosis which can prove to be a very stressful time for the individual and their families and carers. It is therefore important they are offered access to support during this very anxious time. There is a universal offer of information, advice and support from Carers Support West Sussex and robust mechanisms should be put in place to ensure carers awaiting a diagnosis have access to this support.
- Information and advice is key to ensuring the individual and their families and carers can live well with the condition. Once people have received a diagnosis of dementia, they should be provided with the right level of information and advice in a format that is right for them. There should be a 'no wrong door' approach to how people access information and advice. The provision of information and advice should be well coordinated, with all information providers offering an equitable level and quality of information about, for example, living with dementia, welfare benefits and available support.
- The individual along with those people who are important to them need to be given the opportunity to plan for their future care and contingencies at the point of diagnosis. This plan should be reviewed at regular intervals in the person's pathway. Care planning provides an opportunity for people to be able to draw on their own strengths and assets and identify where additional support is required.

  The Prime Minister's Challenge on Dementia recommends that a named co-ordinator is appointed who has a good understanding of the person and their needs along with how to navigate the health and social care system. In West Sussex, the GP is the named co-ordinator who is responsible for ensuring that the person receives regular care plan reviews and is linked into local support networks.
- Any information, advice and support following diagnosis should be tailored to include the needs of people under the age of 65, people with alcohol related dementia, people with learning disabilities, black and minority ethnic (BAME) communities, religious minority communities and Gypsy and Traveller communities and people from the LGBT+ community.
- The Prime Ministers Challenge also recommends that people diagnosed with dementia and their families and carers should be given information about how they can participate in research after diagnosis and at each stage in their journey.

DIAGNOSING WELL

Early Onset Dementia

Younger people with dementia (under the age of 65) face different issues, not least that they are more likely still to be working or have a young family. As this disease has been considered 'rare', there is often a long wait to diagnosis as other conditions are explored. Support designed for older people with dementia is often not suitable. This means that people with early onset dementia can find themselves isolated within the community.

Lesbian, gay, bisexual and transgender + (LGBT+) and Dementia

For older LGBT+ people, living with dementia can be additionally stressful. Not only is this group of people less likely to have family members and children to provide support. They are also more likely to live on their own and be single. Many LGBT+ people fear that mainstream care services will not be willing or are not able to understand how to meet their needs. As a more vocal and open generation follows behind, dementia services need to consider how they will meet the challenge.

Learning Disabilities and Dementia

People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s. However, in West Sussex, the pathway to diagnosis is patchy.

Symptoms of dementia can present differently so that people often do not recognise changes as being dementia related. Because of this, opportunities for early intervention are lost. It is important that people with learning disabilities are offered baseline assessments and regular reviews so that signs of dementia can be picked up at an early stage. It is also important for those people and organisations supporting them to be aware of the signs of dementia and how to care and support the individual as their dementia progresses.

Sensory Loss

It is important that hearing and sight are both checked for and ruled out as a potential dementia before the person is referred for a diagnosis. This can prevent an unnecessary referral to the Memory Assessment Service and anxiety to the individual.

Living with both dementia and sensory loss presents challenges. Dementia can cause problems with vision and hearing, without an eye or ear condition causing it, and this may make it difficult to recognise the loss of hearing or eyesight as it develops. Regular hearing and sight tests, technological aids, environmental improvements, and accessible information and communications can all make a big difference for people with dementia and sensory loss.

Black Asian & Minority Ethnic Communities (BAME) and Dementia

Among the UK's BAME population there are lower levels of awareness of dementia and high levels of stigma associated with the condition. People from BAME backgrounds are under-represented in dementia services and tend to present to services later. There needs to be an emphasis on how we reach people from these communities with information about prevention and identifying the early signs. Services designed to support the person need to be culturally sensitive.

Alcohol Related Dementia

Alcohol related dementia is more common in people in their 40s and 50s and comprises about 10% of the cases of young onset dementia diagnosed. The condition is poorly understood and often missed by health professionals. Patients struggle with the 'double stigma' of dementia and alcohol addiction and often end up in accident and emergency units because of a lack of community services or clear pathways to support. They also experience longer stays in hospital.[2]

Key issues and Challenges

- The fear of stigma can prevent a person from accessing a diagnosis, there is a need for good information to be available about dementia and the benefits of diagnosis.
- Early signs of dementia not being recognised in people with learning disabilities and baseline assessments not taking place.
- Sensory impairment and other conditions can be confused with dementia. It is important for these to be ruled out before referral to the MAS/DAS.
- Long waits to diagnosis leading to people dropping-off the waiting list.
- Lower rates of diagnosis among people from BAME communities and in people with Alcohol Related Dementia.
- At the point of diagnosis, people receive a raft of information and advice, but it is not always easy for them to know where to access information and advice at a later stage.
- A system that is complicated and disjointed where people can get 'lost' along the way particularly when their needs change.
- Care plans not being shared with all those involved in the person's care.
- Services staying connected to the person living with dementia.

Our goals	What we mean
People recognise the early signs of dementia. They know what steps to take to receive a diagnosis and the benefits of diagnosis.	• Dementia awareness raising through dementia friends training, media communications, social networking. • People and organisations supporting the person suspected of having dementia in different settings such as housing support, residential and nursing care are skilled in identifying the symptoms and know what steps to take to support people to receive a diagnosis. This includes people and organisations supporting people with learning disabilities, younger people and people with alcohol related dementia. • A baseline assessment of the level of functioning for people with learning disabilities should be recorded at an early age so that any reduction in ability can be linked to the possible development of dementia. • For cognitive impairment and all other conditions such as hearing and eye sight to be assessed and ruled out before a referral to the MAS/DAS.
All groups of people to receive a timely diagnosis including younger people with alcohol related dementia, people with learning disabilities and people from minority groups.	• For all groups of people suspected of having dementia to receive a timely quality diagnosis in an appropriate setting within a specified number of weeks. This includes people under the age of 65, people with alcohol related dementia, people with learning disabilities and people from BAME and minority groups such as Gypsy and Travelling Communities. • For people who are deaf or hard of hearing or have a visual impairment are identified, with correct support and where appropriate onward referral to the MAS/DAS. • The referral rate for people from BAME groups to reflect the ethnic makeup of that geographic area. • Support is available for the person being assessed and their families throughout the diagnostic process. • For people in care settings showing signs of dementia to receive an alternative diagnosis where the full memory assessment process would not be in the best interests of the individual. • GPs and practice nurses to use long term conditions clinics and health campaigns (e.g.: seasonal flu) to consider whether older people at risk of dementia have symptoms that may require further consideration.
Improved access to information and advice	• People diagnosed with dementia and their family or friend carers have easy access to information on planning and making choices about their care at the end of life. Information and advice should be joined up and easily accessible throughout the person's journey and as their needs change. • Information and advice providers should offer a 'no wrong door' approach to the level and quality of the information they provide.

Improved access to good quality joined up support before and after diagnosis	• People awaiting a diagnosis along with their family and friend carers have access to joined up support whilst they await their diagnosis. There should be a robust referral route to providers that will provide support without a formal diagnosis of dementia such as Carers Support West Sussex. • People receiving a diagnosis of dementia from the DAS/MAS together with their family or friend carers receive an offer of support following their diagnosis. This should include an extensive group programme. • Family carers should be given the opportunity to speak openly about the diagnosis their loved one has received either with them or separately. • Post-diagnosis support to be tailored to include the needs of people under the age of 65, people with alcohol related dementia, people with learning disabilities, black and minority ethnic (BAME) communities, religious minority communities and Gypsy and Traveller communities and people from the LGBT+ community.
People have the opportunity to plan for their future care and contingencies along with those around them	• A care plan is developed together with the person and those involved in their care that is individual to the person's needs. A plan that includes the person's choices, hopes and aspirations which can guide professionals involved in their care. The care plan should consider cultural identity and faith etc. • The care plan should be used across the whole health, social care and community sector to ensure that all organisations understand the needs of the person with dementia, including recognising any additional conditions the person might have and their potential impact. Emergency and contingency planning needs to be embedded within the care and support plan. • Ongoing review of the care plan at least annually or more often if the person's needs and wishes change, by a health or social care professional skilled in care planning. • There is an easy route back into support if required at any point in the person's journey to ensure that those people affected by dementia do not fall through the 'net'. • People with dementia to be given the opportunity to plan for their end of life care and preferences, beliefs and values regarding their future care. This should take place at diagnosis, review or when circumstances change. There should be opportunities for the individual to change any decisions they have made.

DIAGNOSING WELL

Examples of Local Key Initiatives**

Dementia Assessment Service - a one-stop model to streamline dementia diagnosis within secondary care.

DiADeM (the Diagnosis of Advanced Dementia Mandate). DiADeM is a tool to support GPs in diagnosing dementia for people living with advanced dementia.

West Sussex County Council (WSCC) Supporting Lives Connecting People - Prevention focused drop-in sessions alongside pre-booked Talk Locals meetings. Drop-in sessions help people to access local advice, information and services to support them to stay as independent as possible in their local communities.

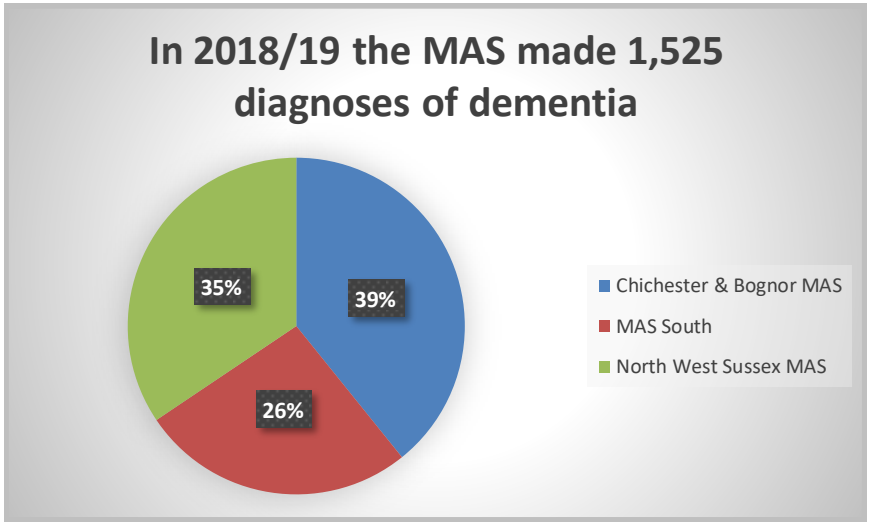
**commissioned and non-commissioned services

DIAGNOSING WELL – Key Data

3% of non-White British people diagnosed through the MAS in 2018/19

Post diagnostic interventions provided by MAS in 2018/19:
1251 people with dementia
990 family and friend carers

1233 referrals into the Dementia Adviser service in 2018/19



In the last 4 years the average percentage of referrals **waiting more than 4 weeks** for an assessment from the MAS was 40% in Coastal, 66% in Crawley and 57% in Horsham and Mid Sussex 57%.

Memory Assessment Service	2014/15	2015/16	2016/17	2017/18	2018/19	%age change (median) over time
Total Referrals	3488	3624	3641	3572	3921	4% increase
No. diagnoses of Dementia	1322	1460	1382	1409	1525	5% increase
%age of diagnoses of dementia to referrals	38%	40%	38%	39%	39%	NA

In 2018/19 4004 people accessed information and advice commissioned through Public Health social support services

In 2014 the diagnosis rate stood at 46%, in November 2019 it was 66.1%

SUPPORTING WELL

West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people living with dementia and their family and friend carers receive high quality care and support throughout their journey from health and social care staff skilled in good dementia care **that is individual to the needs of the person with dementia.**

Overview

- The person with dementia and their family and friend carer need to be put at the centre of their care. It is essential they know how to access information and support as their dementia progresses and have opportunities to plan ahead for their future care while they are still able to do so.
- For many people dementia is not the only long-term condition they live with and they need to be enabled to manage the dementia and other conditions as much as possible for themselves. This requires a joined-up pathway of support, including between primary, community and hospital provision. The valuable contribution provided by voluntary and community sector providers as well as many smaller community-led providers is also essential and needs to be included in the pathway of support. People should not have to re-tell their story every time they encounter a new service and providers need to ensure that information (such as care and support plans and advance care and support plans) can be easily transferred between different care settings.
- The best place for someone living with dementia is to remain at home independently for as long as possible but the progressive nature of dementia means that often people will develop increasingly complex needs. People with dementia and their families need to be confident that, when a need arises, they can receive the support they need without having to make multiple approaches. West Sussex County Council (WSCC) Adults Services, Proactive Care and Specialist Dementia Care Services work together to provide a joined-up offer of support. Care is coordinated and there is less of an emphasis on reactive crisis intervention and unplanned care/hospital towards independent health and wellbeing. Services work with the individual to enable them to see the value they themselves bring and the resources around them.
- People with dementia need to live in suitable housing that meets their changing needs and there needs to be information and advice about housing provided at the point of diagnosis.
- Local house planning needs to reflect the growing need and the rise in prevalence across the county. Housing providers can also play a key role by supporting Dementia Friendly Communities and ensuring their staff are dementia aware. They can help identify the symptoms of dementia and encourage people to seek support.
- For many people with memory loss, living at home can be challenging and often just a small intervention such as a personal alarm can help the person to be able to remain at home for longer and provide peace of mind for their families and carers. There needs to be a clear offer of equipment and assistive technology that optimises the individual's wellbeing and independence. Technology enabled care services (TECS), that is technologies such as telecare and telehealth, and self-care apps can help people to manage and control chronic illness and maintain their independence.
- Extra Care Housing can be an attractive option for someone living with dementia as it offers the security of having care staff on hand but without losing the independence of living in your own home. In West Sussex, there are 13 Extra Care schemes that the County Council nominate customers to, of these 12 schemes have commissioned care contracts through the Council.
- As the condition progresses, it may become necessary for the person with dementia to require some additional care and support to enable them to live at home safely. It is recognised that good quality domiciliary care and access to community-based opportunities for active engagement can contribute to maintaining a person's independence, reduce social isolation, prevent admission and/or delay the permanent admission to care homes and/or hospital. The Council continues to actively engage and support the market development of care and support at home providers to ensure excellent delivery for people accessing these services.

SUPPORTING WELL

- For those people whose needs have increased to the point they are unable to live at home, a residential or nursing care home setting may be more appropriate. Support should be easily accessible for the person and their families and carers to be able to make the right decision about their future care planning including how it will be funded. In West Sussex, the largest number of specialist dementia care homes are located in the Coastal area (55%) with only 5% and 9% in Crawley and Horsham respectively. As a local authority West Sussex County Council (WSCC) has a responsibility for quality of provision, market shaping and sufficiency of supply in its local area, however this is reliant on working with other partners including local planners, health, care providers and on staffing.
- For people with dementia there is a greater risk of an unnecessary hospital admission, together with longer stays and delays to discharge. A national Care Quality Commission (CQC) thematic review showed that in most NHS acute trusts, people with dementia stayed significantly longer and were more likely to be readmitted or die in hospital. Wherever possible, admissions to hospital for people with dementia should be avoided and where this is not possible, stays should be as short as possible. Services need to work together to provide a joined-up approach to supporting the person at risk of an unplanned hospital admission or delayed discharge.
- Hospitals can be disorientating and confusing places for someone with dementia and there can be issues with eating, drinking and pain relief during their stay. Sensitivity, compassion and empathy are core qualities that doctors, nurses and all hospital staff should have for their patients, as are listening and communicating. Hospitals should provide dementia friendly environments.
- All hospital staff should be skilled in dementia care at a level appropriate to them. West Sussex hospitals have robust dementia training programmes in place that are targeted at all levels of staff. Family and friend carers are key to the wellbeing of the person with dementia whilst the person is in hospital and they also need support at this difficult time.
- For carers, a stay in hospital either for them or the person they are caring for can be particularly stressful. Carers Support West Sussex has teams working within hospitals offering support with discharge planning and information and advice. Additionally, John's Campaign, a movement to help NHS staff recognise the importance of working with family carers as equal partners in the care and support of people with a dementia, is being used by hospitals in West Sussex.
- In West Sussex, services such as Home from Hospital, Take Home & Settle and Relative Support ensure the patient and their family and friend carer are supported to return home safe and well.

Key issues and challenges

- There is a lack of clarity about eligibility for dementia services.
- The All-Party Parliamentary group (APPG) report from 2016 suggested almost 7 in 10 people with dementia also have one or more other health conditions. However, services often work independently of each other and there is little joined up working.
- Services designed to keep people at home are stretched and struggle to meet demand.
- People with dementia from the LGBT+ community can feel that services are not able to understand how to meet their needs.
- Crises are common in people with dementia and can lead to unplanned admissions to hospital and residential care, but services designed at keeping people at home are stretched and struggle to meet demand.
- Lack of 24/7 crisis support.
- Falls and fractures are a particular issue for people with dementia and can lead to hospital admission and loss of independence. Lower-body strength exercises and balance exercises can help prevent falls and avoid the disability that may result from falling.
- People with dementia often experience longer stays in hospital, delays in leaving hospital and reduced levels of independent functioning.[3]
- Delays in discharging people with dementia safely from hospital because of issues such as finding placements and packages of care for people living in rural communities or for people with complex and challenging needs; together with delays in social care assessments and funding decisions.
- Sufficient capacity within the care market and recruitment of care staff to meet the needs of people with dementia requiring long term residential and nursing care or short-term respite. Particular issues for people with more challenging needs and people with Early Onset Dementia.
- Over stretched resources including staff and time.
- Gaps in staff training and often lack of confidence in supporting someone with complex and challenging needs.

Our goals	What we mean
For people to be enabled to live independently at home	• People have easy access to adaptations to the home and technology that allows them to live at home safely. For example, ramps, grab rails, movement sensors, personal alarms, trackers. • People with dementia live in housing that meets their needs and house planning reflects the needs of people with dementia. • Housing providers are skilled in dementia awareness. • For the risk of falls to be prevented that are caused through physical inactivity, poor hydration and nutrition, sensory impairment and home hazards. • There is a co-ordinated offer of information, advice and guidance that enable people to have choice and control over their health and independence. • There is sufficient local provision of care and support at home where more support is required. For services to be flexible in how they support the person living with dementia and help people to help themselves more through focussing on outcomes rather than processes. • People with hearing or sight loss have access to regular hearing and sight tests, technological aids, environmental improvements, and accessible information and communications.
For people with dementia to be able to access joined up health and social care and community support throughout the progression of their dementia	• The person with dementia and those around them need to be put at the centre of their care. • Dementia needs to be seen as a long-term condition that requires on-going management over a period of years. Inevitably it is very common for people with dementia to also have other long-term conditions. Therefore, it is essential that people with dementia, their families and carers know how to access support as their dementia or other health conditions progress. This requires an integrated pathway of support, including between community and hospital provision. • People should not have to re-tell their story every time they encounter a new service, and to not get the support they need because different parts of the system do not 'talk' to each other or share appropriate information and notes. • Service providers to ensure that information (such as care and support plans and advance care and support plans) can be easily transferred between different care settings (for example home, inpatient, community and residential care). • Patients should experience a smooth and timely transition from hospital back to their home environment. Hospital and community teams need to work together from admission, to tackle factors that could prevent a safe and timely transfer of care from hospital and to ensure the patient is at the heart of any discharge planning.
Dementia and carer friendly health and care settings	• If thought is not given to the way that a person with dementia interacts with their environment, this can result in increased agitation and behaviours that challenge, falls, confusion and can hinder the delivery of person-centred care. A dementia-friendly environment is one where buildings and physical environments do not prevent people with dementia from accessing them. • The role the family and friend carer plays in the care of the person with dementia cannot be under-estimated and in all care settings they should be: identified and supported and recognised as partners in their loved one's care.

Approaches to care and support that are individual to the person's needs and for the person to be enabled to self manage their dementia and other conditions	• Support is built around the individual with dementia, their carer and family and provide them with more choice, control and flexibility in the way they receive care and support – regardless of the setting in which they receive it. • The individual and their family and friend carers are enabled to see the value they themselves bring and the resources around them. • Care and support are delivered in a culturally appropriate manner in order to be accessible to people from BAME and religious minority communities. • Ease of access to information and advice and advocacy services where there is not an appropriate person to represent the individual. • Life Story work is an activity in which the person with dementia is supported by staff and family members to gather and review their past life events and build a personal biography. It is used to help the person understand their past experiences and how they have coped with past events. • People with dementia should be given the opportunity to express their own views and opinions about their care in a format that is appropriate to them i.e. through visual aids, simplified text etc. • People with dementia are enabled to manage their dementia and other long-term conditions themselves.
Compassionate care and support from staff skilled in dementia	• Education, training and development opportunities available for those people and organisations providing care and support for people with dementia at a level that fits with their individual responsibilities. Education and training should focus on: ○ identifying symptoms of dementia and know what steps to take to support people to receive a diagnosis. ○ acquiring greater awareness and understanding of dementia, so that they can help to ensure people are diagnosed and supported earlier. ○ becoming better equipped to help people in crisis to remain at home or return home after a hospital admission. ○ having awareness of the impact of dementia on the person living with the condition and their families. ○ Getting to know the person, their history and interests, and understand how dementia is affecting their life in order to be able to offer care and support that is individual to them. ○ Giving consideration to the person's individual characteristics including age, disability, gender reassignment, marriage and civil partnership status, race, religion and belief, sex and sexual orientation. ○ Starting and holding difficult emotionally challenging conversations such as end of life care planning. • For there to be a framework for dementia training to ensure all people receive training relevant to their role so that there is a workforce across the dementia care system that has the right skills, behaviours and values to support people living with dementia and is equipped to do so. • The Framework for Enhanced Health in Care Homes (EHCH) is based on a suite of evidence-based interventions, which are designed to be delivered within and around a care home in a coordinated manner. • All healthcare assistants and social care support workers to have undergone training as part of the national Care Certificate. Staff competency and accreditation in dementia care skills should be regularly monitored and reviewed. • Workers supporting people with learning disabilities and dementia to be skilled in supporting someone to remain in their normal care setting for longer following their diagnosis. When this is no longer possible, and the person needs to move into a dementia specialist facility, care workers should be trained in supporting the person with both their dementia and learning disability needs.

For support to be in place to avoid wherever possible unplanned admissions to hospital or inpatient facilities. Where hospital admissions are required, for these to be as short as possible.	• Wherever possible, admission to hospital and inpatient facilities should be avoided by a community crisis response and social care support for both the person with dementia and their family and friend carer. Where home treatment is not possible, patients should receive compassionate care by skilled staff, in dementia and carer friendly environments. • The person living with dementia along with their family and friend carer should be supported to develop a contingency plan as early on in their journey as practical. • For only the most complex patients to need admission to an inpatient bed. Where admission is needed, the stay will be as short as possible with integrated discharge support to ensure that discharge home or to care/nursing home is not delayed.

The risk of a crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined up offer of support	• Early conversations should take place the person living with dementia and their family and friend carer so that they can plan ahead for their future care while they are still able to do so.
	• Wherever possible, admission to hospital, inpatient facilities or residential care should be avoided by a community crisis response and social care support for both the person with dementia and their family and friend carer.
	• The following contributory factors to a crisis should be identified and interventions provided where necessary:-
	  ○ Family and friend carers unable to cope with their caring role.
	  ○ The person with dementia presenting behavioural and psychological characteristics.
	  ○ Physical health problems.
	  ○ Social factors related to the person with dementia or their environment.

People with dementia and their families have a good experience of support provided by Care Homes and that there is sufficiency of quality, affordable provision within West Sussex that reflects the needs of diverse communities.	• Staff in all care homes to be able to identify the symptoms of dementia and know how to access support. • Care staff know what to do to avoid an unnecessary hospital admission. • There should be mechanisms in place for supporting excellent dementia service leadership. • The family and friend carer should be considered partners in the care of the resident. • There should be a diverse provider market that can deliver culturally sensitive support and support for people from the LGBT+ community. • Care homes should develop good links into their communities and become part of their local dementia friendly community.

SUPPORTING WELL

Examples of Local Key Initiatives**

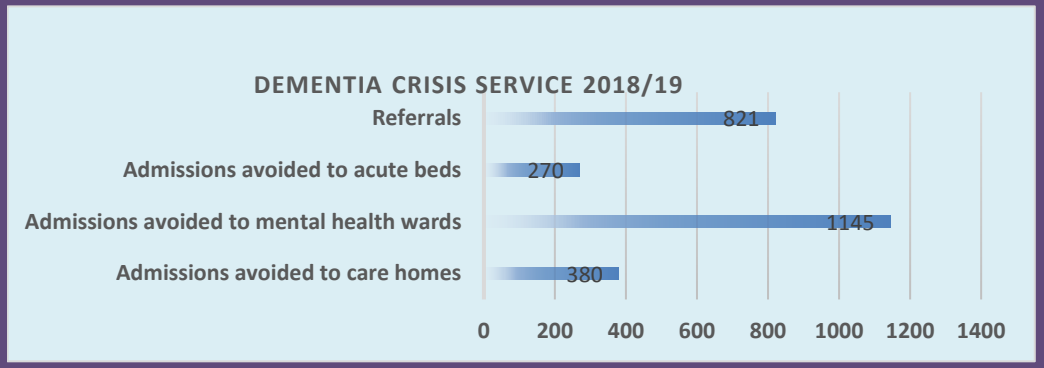
- The Council's Dementia Learning Framework on the Learning & Development Gateway provides easy access to learning about dementia for all people and organisations supporting someone with dementia.
- Support for people with dementia and long term health conditions across Coastal West Sussex from the Community Proactive Care Plus teams.
- Time for Dementia programme provides undergraduate healthcare professionals with on-going, regular contact with a person with dementia and their carer.
- Dementia friendly Hospital Charter being rolled out by Western Sussex Hospitals Trust.
- 'This is About Me' and 'Knowing Me' tools to provide key information for hospital staff about their patients.
- 'Connect with dementia' – a volunteer service being run at Crawley Hospital and Zachary Merton in Rustington
- An in-hospital Carer Wellbeing Service for family and friend carers through Carers Support West Sussex.
- Home First – Discharge to Assess model. A service that enables people to be effectively and efficiently discharged from hospital.
- 'Hospital to Home' clinic at Horsham Hospital for providers to come and share information with patients.
- Dementia champions across Intermediate Care Units and considerable investment to improve environments to make them more dementia friendly.
- New Dementia In-patient facility that is a Centre of Excellence in Worthing for people living with dementia which will improve the care for both their mental and physical health needs.
- Re-focus of Council's in-house services on delivering support which makes the most of people's wellbeing and independence such as day services, residential care homes and 'Shared Lives' scheme.
- Care & Business Support Service - A Council initiative that provides professional support to local services in the care sector.
- Proud to Care – An initiative run in collaboration with the Council and NHS that works proactively to support the nursing and care sector to develop recruitment, retention and capacity plans and to identify and support providers with workforce training.
- PatchCare® from Caremark - an innovative approach to home care, delivering a wide range of personalised care services. It covers small geographical patches. Clients benefit from regular, more tailored visits throughout the day.

**Commissioned and non-commissioned services

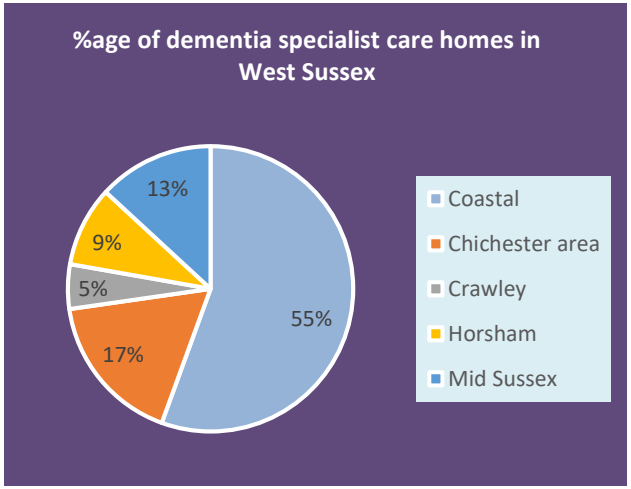
SUPPORTING WELL – Key Data

132 residential and nursing homes in West Sussex specialisng in dementia – offering 5104 beds

In 2018/19 5,327 people used the Home from Hospital, Take Home & Settle and Relative Support services



In 2017/18 there were **2761 per 100,000 emergency admissions to hospital in West Sussex** for people with dementia* 848 less than nationally
*Dementia: Direct standardized rate of Emergency Admissions (aged over 65)[7]



Around **65 referrals each month** into the Dementia Support Service with 80% coming from family carers

In 2017/18 Carers Support WS received 1293 referrals for equipment for independence

13 Extra Care Housing schemes commissioned by the council

5,100 referrals to the Hospital Carer Wellbeing service in 2017/18

LIVING WELL

West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people living with dementia are supported to live well with dementia by enabling them to: Stay socially active; Keep healthy and well; Access safe and welcoming communities that are responsive to the needs of people with dementia; Have access to quality information about dementia and the support available such as community activities, leisure and transport; Receive support to engage in meaningful activity, doing something that people enjoy or are interested in; and for family and friend carers to receive the support they need to be able to continue in their valuable caring role.

Overview

- There is potential for people with dementia to live meaningful and satisfying lives, but this requires support from all those people and services surrounding the person including their own community.

  Breaking down the stigma of dementia is key and initiatives such as 'Dementia Friendly Communities' can help people to access their local communities and reduce the risk of social isolation and loneliness. People with dementia have described a dementia friendly community as one that enables them to:

  - Find their way around and be safe
  - Access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas and post offices)
  - Maintain their social networks so they continue to feel they belong.

  Local Dementia Friendly Community Groups focus on changing public attitudes through the creation of dementia friendly communities so that people affected by dementia have the best possible opportunities to live well. Dementia Friendly Communities in West Sussex have been growing steadily during the time of this Framework and there is now a Local Dementia Friendly Community Group in almost every major town in West Sussex with almost 300 members. Members include local businesses, community groups, faith groups, schools and colleges, libraries, museums, shopping centres and charities as well as health and social care providers. Local Groups are led in the main by volunteers and without the right support to build capacity this work is unsustainable and over time there will be an impact on how far dementia friendly communities can grow and develop. There needs to be a coordinated response to how Local Dementia Friendly Community Groups are supported and funded.

- Caring for someone with dementia can put a huge strain on the carer's physical and mental health and finances. It can also strain, at times to breaking point, the relationships with other family members. A family and friend carer needs support so that they can continue in their caring role and enable their loved one to live well with dementia.

  Carers should be offered training about dementia, its symptoms, providing care and the changes to expect as the condition progresses. They should be supported to develop a personalised strategy for their caring role. Training should include support with adapting communication styles to improve interaction with the person they are caring for. The carer also needs advice on how to look after their own physical and mental health and their emotional and spiritual wellbeing.

  Local Authorities have enhanced duties towards carers since the introduction of the Care Act 2014. In West Sussex, there is a consistent offer of support, information and guidance to all carers delivered by a single provider, Carers Support West Sussex. This provides a gateway service to all other carer support services within the County, such as carer break services and more specialist services.

LIVING WELL

- People living with dementia need to have access to a range of activities that promote their wellbeing. They should be affordable, easy to get to and tailored to the person's individual needs. Activities should reflect the changing needs of the person with dementia as their dementia progresses.
- Accessing groups and other activities can be particularly challenging for people who may no longer be able to drive, particularly those living in more rural communities and there needs to be a robust plan for ensuring better transport links and provision that is closer to home.
- There needs to be a community-led support approach to how we meet the challenges faced by people affected by dementia. Community-led support focuses on reaching people at an early stage to help prevent or delay the development of their care and support needs and to enable them to be as independent as possible. Supporting Lives, Connecting People is the name used for delivering community-led support to adults in West Sussex. Sessions known as Talk Locals are held in local communities where people can speak face-to-face with staff from a range of disciplines about their situation and find suitable solutions on the day of the appointment if possible.
- The Council, Clinical Commissioning Group, voluntary and community sector organisations, including smaller providers, deliver a diverse set of services to enable the individual and family and friend carer to live well. These can include daytime activities and short break respite opportunities that provide a much-needed break for the carer from their caring role. Services are delivered either in the person's own home on a one to one basis, or through group activities away from home this can include: day services; outings and dementia cafes. There are also services in place to provide short term support for someone in their own home including emergency respite for the family carer and support for people to settle back at home after a stay in hospital.
- Access to information and advice about living with dementia, welfare benefits and the support available is key to ensuring all people affected by dementia can continue to live well with the condition. Information about services that can support the person and their families and carers should be easily accessible and provided in a co-ordinated way. Information and advice providers should offer a 'no wrong door' approach to the level and quality of the information they provide. In West Sussex, there is a universal offer of information and advice for people with dementia and family and friend carers from Alzheimer's Society's Dementia Support Service and Carers Support West Sussex along with a county-wide information and advice service commissioned by Public Health. In addition, a dementia zone on the West Sussex Connect to Support website provides information about dementia and local services and support.

Key issues and challenges

- Family and friend carers can become cut off from the community leading to social isolation and resultant worsening of health. They need easy access to peer support, carers groups and other initiatives that help them to stay connected.
- Lack of flexible breaks for carers impacting on the carers ability to continue effectively in their caring role.
- Historically low uptake to services from people with dementia from Black and Minority Ethnic and seldom heard groups.
- People from LGBT+ communities having opportunities to participate in services designed to support them to live well.
- For people with Early Onset Dementia to have support to engage in age appropriate activities.
- Sustainable Dementia Friendly Communities - Local Dementia Friendly Community Groups rely mainly on volunteers and on short term time limited financial support which impacts on the sustainability of this work.
- Transport can be a particular challenge particularly for someone living in more rural communities and/or where they can no longer drive.
- More local activities needed for people with dementia and their family and friend carers to participate in.
- Support for people with dementia to take part in non-specialist/mainstream groups and activities.

Our goals	What we mean

People have access to a range of affordable flexible activities that reflects their interests and needs and are appropriate to their age and the stage of their dementia	• Dementia specific services or support to access non specialist/mainstream activities to be designed to meet the needs of all people including those who:
	  ○ do not have a family or friend carer
	  ○ do not have access to affordable transport, or find transport difficult to use;
	  ○ have sensory impairment or physical difficulties;
	  ○ are less likely to access health and social care services such as people from the LGBT+ community, Gypsies and Travellers and black, Asian and minority ethnic groups.
	• Activities thought to benefit the person with dementia include: Physical based activity, Outdoor activity, Reminiscence based, Arts based activities, Music based activities. (A recent systematic review for the What Works Centre for Wellbeing concluded that there was evidence of wellbeing benefits of singing among people with dementia.)
	• Age appropriate activities or support to access non specialist/mainstream activities for people with Early Onset Dementia and Alcohol Related Dementia.
	• Activities are available that are appropriate to the person with dementia as their dementia progresses.

There is a whole community response to living well with dementia in safe and enabling communities	• Dementia friendly communities grow stronger and become sustainable. • There is a coordinated response to how Local Dementia Friendly Community Groups are supported and funded. • All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and action plans. • The roll-out of dementia friends sessions to enable people to learn what it is like to live with dementia. A Dementia Friend learns what it is like to live with dementia and then turns that understanding into action – for example, by giving time to a local service such as a dementia café or by raising awareness among colleagues, friends and family about the condition. • All employers with formal induction programmes to include dementia awareness training within these programmes. • For younger people to be more educated and aware about dementia. • Public sector organisations taking a leadership role by becoming dementia friendly organisations. • Environments and physical settings in the community becoming dementia friendly places with people living with dementia being able to take advantage of open spaces and nature. • There is a proactive approach from services such as Fire, Police and Trading Standards that supports people living with dementia to live safely in their communities. • Public transport that enables people with dementia to be able to participate in a wide range of activities and is welcoming and inclusive.

People can maintain and develop their relationships and be able to contribute to their community	• For people affected by dementia to be enabled to maintain and develop social connections through peer support, carers groups and similar initiatives to help build resilience. • Social action solutions such as peer support and befriending services can also provide practical and emotional support to people with dementia and carers, reduce isolation and prevent crisis. • For family members including dependent children of people with Early Onset Dementia to receive practical and emotional support. • For people with dementia and family and friend carers to be supported to take part in paid and unpaid work.
Carers of people with dementia are able to access information, support and training as needed and feel able to continue with their caring role	• For people with dementia and their family and friend carers to be put at the centre of their care and have access to flexible support that is responsive to their personal interests and needs. For family and friend carers to: • be identified by all those involved in the care and support of the person they care for and treated as partners in their care. • be offered an assessment of their own needs that considers their emotional, physical and social care needs. • have access to psychological therapies. • have access to advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing • access advice on planning for the future. • have easy access to information and advice in an accessible format at every stage in their journey from pre-diagnosis through to end of life and bereavement. • have access to education and advice in a format that is suitable to them, about the most common problems they are likely to meet, its symptoms and the changes to expect as the condition progresses. For the family and friend carer to have support to build their skills and develop an individual strategy for supporting the person they care for. • have an opportunity to access one-to-one support and peer support in a format that is suitable for them, so as to be able to link up with carers in a similar situation. • be able to access support at a location they can get to easily. • have the offer of regular vital breaks from caring. This can be for a few hours, a day or a week, perhaps longer. It may be provided at home or elsewhere. It could be a regular, planned arrangement, or it may be more occasional. This should include emergency respite if necessary. • have the opportunity to pursue interests that are individual to them as well accessing or maintaining paid or unpaid work.

LIVING WELL

Examples of Local Key Initiatives**

- Training for family and friend Carers such as Carer Information and Support Programme (CrISP) run through Alzheimer's Society and 'Understanding Dementia workshops run through Carers Support West Sussex.
- New Tyne Resource Centre in Worthing offer long stay residential placements, respite and day service for people over the age of 40 who have a diagnosis of dementia.
- The Council's in-house Shared Lives service for people with dementia.
- Dementia Friends training being delivered by Dementia Champions throughout West Sussex and accessed on-line.
- Admiral Nurses - supporting family carers of people with dementia in the community in the north of the County.
- Jointly commissioned county-wide Short Breaks service for family and friend carers through prime providers - Age UK West Sussex, Independent Lives, Carers Trust East Midlands, Age UK Horsham District and Guild Care.
- Specialist support for people with Early Onset Dementia that includes an overnight residential Break twice a year, Neil's Club in East Grinstead, Cando@K2 in Crawley and Centre Club in Worthing.
- Dementia Support at Sage House in Tangmere, offering a Wayfinding service to help guide families through their personal dementia journeys, as well as day care, a range of activities for those living with dementia and their carers, therapy rooms, a salon, a smart zone, and a café.
- Countywide activities to stimulate cognition and provide social interaction such as: Sporting Memories, Dance Well and Thrive, gardening clubs, community sheds.
- Herbert Protocol rolled out by Police Service. For carers to compile useful information about the person they care for that can be used in the event of a vulnerable person going missing.
- Safe and Well visits - a free service carried out by West Sussex Fire & Rescue Service.
- Carers Support West Sussex Dementia Wellbeing programme offering practical support and information to carers.
- Library service offering Memory Management Tickets, Books on prescription, Digital Library Plus Home Visits, Reminiscence collections, drop-ins and Melody for the Mind groups.
- West Sussex Mind helping people over 65 in Bognor and Chichester and Midhurst who are feeling low, have depression, anxiety or other mental health problem, or are simply feeling isolated.

**commissioned and non-commissioned services

LIVING WELL KEY DATA

In 2018/19 2540 people accessed Day Activities commissioned by Public Health.

10 Local Dementia Friendly Community Groups in Arun, Burgess Hill, Chichester, Crawley, East Grinstead, Haywards Heath, Horsham District, Worthing, Selsey and Adur with a **membership of around 300**

32.0% of carers have as much social contact as they would like. **63.5%** say they have had no or not enough support*.
**Alzheimer's Research UK*

5 Council-run Older People's Specialist day services – Glebelands, The Laurels, The Rowans, Chestnuts and Judith Adams

32,540 Dementia Friends in West Sussex and **127** champions

5 service user review panels hosted by Alzheimer's Society

Carers Support West Sussex currently have around 25,000 registered carers and **almost 5,000 identify** themselves as caring for someone with dementia.

Short Breaks service offering carers a break from their caring role in Adur, Arun, Chichester, Crawley, Horsham, Mid Sussex and Worthing

63% of carers for people with dementia are retired while 18% are in paid work. 15% of dementia carers say they are not in work because of their caring responsibilities.*

*Alzheimer's Research UK

In 2018/19 almost **200 carers** of people with dementia accessed the Carers Health & Wellbeing Fund and were granted more than **£53,000** to help them in their caring role.

DYING WELL

West Sussex County Council and the Clinical Commissioning Group are committed to ensuring that people with dementia and their families are supported to plan ahead, receive good end of life care and are able to die in accordance with their wishes.

Overview

- Research shows that people are more likely to die in the place of their choice if their wishes are known and documented in advance. The government has said that all people with a diagnosis of dementia should be given the opportunity to plan in advance for their care early on to ensure the person and their carer are fully involved in decisions on care at end of life. Open communication that involves the individual and families in decisions, and is responsive to their needs is vital and can vastly improve their experiences.

  It is important to have early conversations with people with dementia and their carers so that they can plan ahead for their future care while they are still able to do so. This reduces the likelihood that difficult and emotional decisions have to be made in crisis, when the wishes of the person with dementia cannot be taken into account.

  Assessment and management of distressing symptoms at the end of life can be greatly helped by a detailed knowledge of the individuals' prior wishes. These kind of conversations can often be difficult and it is important that staff involved in these have the necessary training to feel confident about starting the conversation with sensitivity.

  Planning with the 'whole family' and establishing that individuals have identified advocates to support them with health and welfare decision-making is crucial to ensuring that the wishes of the individual living with dementia are reflected in the actions taken. This approach is also helpful for the person's family as they will be directed to services that can support them once their loved one has passed away, such as bereavement services, as well as the formalities that will need to be carried out.

  In West Sussex, the CCGs along with, Sussex Community NHS Trust, Sussex Partnership NHS Foundation Trust, Western Sussex Hospitals Trust and local hospices and services have endorsed an Advance Care Plan 'Planning Future Care' to identify wishes and preferences for future care. This is being implemented across West Sussex, in the community, care homes, and virtual wards.

- People nearing the end of their life need to receive coordinated, compassionate and care that is individual to their needs. This includes palliative care for the person with dementia and bereavement support for carers. Care needs to be delivered by skilled, trained and compassionate staff throughout the person's life journey. Hospices can play an important role in supporting staff to care for people with dementia, as well as caring directly for people with dementia especially where the person has more than one long term condition. In West Sussex, local hospices and specialist palliative care providers are commissioned to provide end of life training. The training includes specific programmes for care homes. The CCG also supports an education package for NHS End of Life Care Champions.

DYING WELL

- The End of Life Care Hub in Coastal West Sussex (ECHO) helps to improve identification of people in the last year of their life; share care plans between services; and provide a more responsive, proactive and person-centred offer of care. The ECHO hub maintains a register of people in their last year of life accessible for clinicians; it provides patient and carer support through a website and 24-hour telephone line. It plans for newly identified patients and responds and reacts to patients' changing needs by co-ordinating access to services.

- It should be recognised that care for one another in times of grief and loss is everyone's responsibility and supportive networks have a key role. The resources in our communities can be harnessed to help improve the experience of the individual. Compassionate Communities is a new initiative from West Sussex that is looking at ways communities can come together to support people during illness, dying and bereavement. In line with National ambitions for palliative and end of life care, they want people in West Sussex to be able to say; "I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways."

Key Issues and Challenges

- Planning future care and end of life support not taking place early enough in the pathway.
- Advance care plans where they exist are not always being shared with all those involved in the person's care.
- Hospital staff caring for people in the last stages of their lives are often unaware of the person's end of life wishes.
- People dying away from their usual place of residence or in a place that is not of their choosing.
- People with dementia may experience problems with thinking, memory, behaviour and mobility. It can be difficult to recognise when someone with dementia is nearing the end of their life.
- Managing pain where there are challenges with communication.
- The need to ensure that families and carers receive the right level of bereavement support and counselling.

Our goals	What we mean
People living with dementia together with their families and carers are enabled to make decisions about their future care	• People living with dementia, their families and carers complete advance care plans as soon after diagnosis as possible and that these are reviewed on a regular basis. • People assessed as not having capacity, with no family or friends are referred to an Independent mental Capacity Advocate as appropriate and supported to plan their care. • The advance care plan to be shared with all those health and social care professionals involved in the individual's care.
There is support for people to die with dignity in a place of their choice	• People are informed of options about end of life and are given the appropriate support, respect and dignity to die in the place they chose. • People are not admitted to hospital unnecessarily in the last weeks or days of their life nor delayed from being discharged from hospital. • There is a framework for dementia training to ensure all staff receive training relevant to their role. • There is a workforce across the dementia care system that has the right skills, behaviours and values to support people living with dementia in the end stages of life and is equipped to do so.
People with dementia approaching the end of life, should experience high quality, compassionate and joined-up care	• Care staff and family and friend carers are equipped with the ability to develop their knowledge, skills and behaviours in order to deliver co-ordinated, compassionate and person-centred end of life care for people with dementia. • People with dementia at the end of their life receive emotional or spiritual support.
Families and carers are provided with timely co-ordinated support before death, at the time of death and bereavement	• For all those people involved in end of life care, e.g. the GP, district nurses, care staff, speech and language therapists etc to communicate reliably with each other. Without good information-sharing, a person is less likely to receive the care they need. This should extend to ensuring the family understands what is happening and are updated regularly. • Families and carers receive bereavement support at a time that is right for the individual or family. • There is support and signposting available for friends and family going through the grieving process.

DYING WELL

Examples of Local Key Initiatives**

- The End of Life Care Hub for Coastal West Sussex (ECHO)
- The Clinical Commissioning Group's directly commission End of Life education with local hospices and specialist palliative care providers that are open to partners. An education package for NHS End of Life Care Champions has also been supported.
- The Admiral Nurse Service which provides a proactive approach to ensuring family cares receive support and specialist training and education in their caring role particularly at times of crisis and end of life. Admiral Nurses also help with conversations around end of life and transition to residential care.
- Dementia Community Matrons in Adur, Arun and Worthing who support the individual and their families and carers at the end of life.
- End of Life Champions sitting within SPFT Dementia services.
- Public Health currently producing a bereavement pathway.
- Time to Talk – talking therapies services in West Sussex - Bereavement and Reactions to Loss.
- Specialist carer bereavement support through Carers Support West Sussex.
- County-wide WSCC Supporting Lives, Connecting People Talk Local Hubs and Community Drop-in sessions.
- Care homes with Gold Standard Framework accreditation.

**commissioned and non-commissioned services

DYING WELL KEY DATA

In 2017/18 **75.5%** of people with dementia over 65 in West Sussex died in their Usual Place of Residence. 7% higher than nationally.[7]

In 2017/18 **24%** of people aged over 65 in West Sussex died in hospital. 6% lower than nationally.[7]

Echo Evaluation Findings:-

83% of Echo patients with a known preference died in their preferred place. Only 13.3% of people on the Echo caseload died in hospital.

Rate of admission to hospital in the last year of life was significantly lower for those referred to Echo than those who were not.

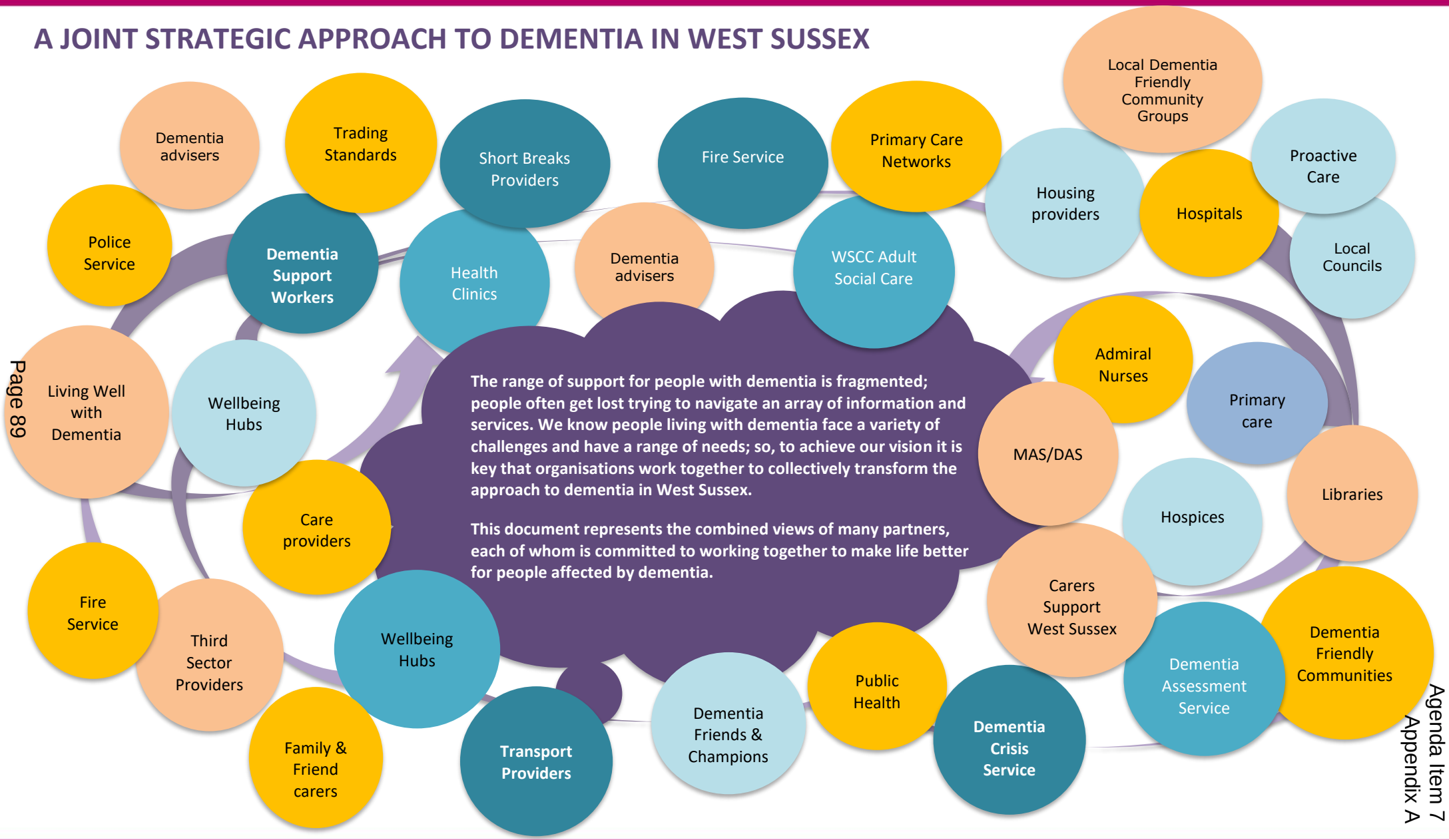
Average hospital length of stay in the last year of life for Echo patients was lower than for people who were not referred to Echo.

In England and Wales, the number of people living with dementia who need **palliative care will almost quadruple by 2040.[8]**

Dementia is now one of the top five underlying causes of death in the UK and **one in three people** who die after the age of 65 have dementia[5]

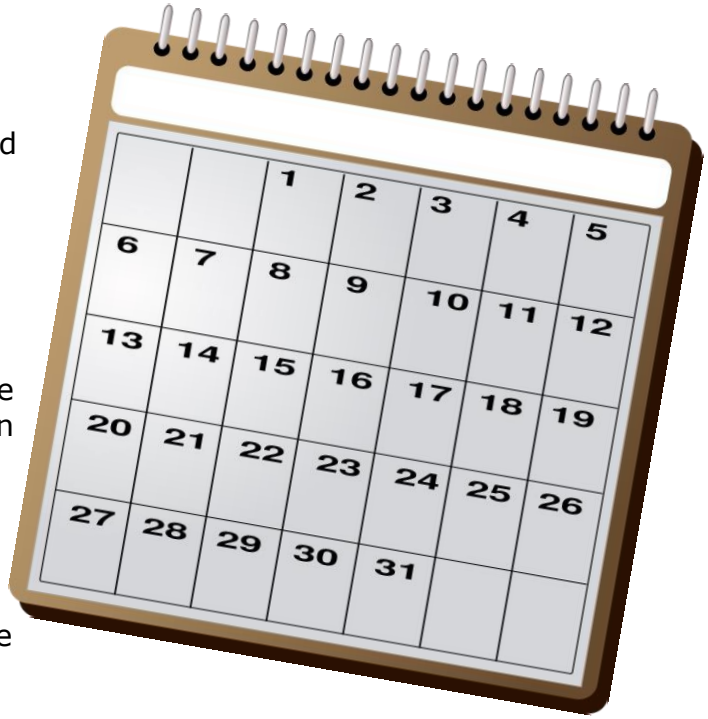
In the UK, **nearly two thirds of people with dementia are women,** and dementia is a leading cause of death among women - higher than heart attack or stroke.[6]

A JOINT STRATEGIC APPROACH TO DEMENTIA IN WEST SUSSEX



MONITORING DELIVERY AND IMPACT ACROSS THE PATHWAY

The delivery plan sets out how West Sussex County Council and the Clinical Commissioning Group plan to monitor the progress being made with the goals set out above and looks at what can be achieved with current resources. An additional section has been included that looks at what can be achieved with a little and much more funding.



It is vital that we assess whether this strategy is making a demonstrable difference to the experience of people living with dementia and their family and friend carers. We know that to really meet the needs of the individual, it is important to listen to them. We will therefore involve people living with dementia and their families in helping us achieve the aspirations set out in this strategy and will continue to re-visit our vision to ensure the voice of lived experience not only remains central to the strategy but helps to measure the impact of it.

Learning from the first dementia strategy tells us that it is imperative we have systems in place for decision-making and accountability. A Dementia Strategic Partnership Group will be established that will monitor the progress of this Strategy, identify gaps and work together to help find solutions.

APPENDICES

APPENDIX A - OUR GUIDING PRINCIPLES

These are based on the five Dementia 'We' Statements published in 2017 by the National Dementia Action Alliance. They reflect what people with dementia and carers say are essential to their quality of life.

These statements were developed by people with dementia and their carers, and the person with dementia is at the centre of these statements. The "we" used in these statements encompasses people with any type of dementia regardless of age, stage or severity; their carers; families; and everyone else affected by dementia.

These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law and are a rallying call to improve the lives of people with dementia. These Statements recognise that people with dementia should not be treated differently because of their diagnosis.

Carers - We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.

Community/Isolation - We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.

Independence/Interdependence/ Dependence - We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

Research - We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

Carers - We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

APPENDIX B - REFERENCES

1 Prime Minister's Challenge on Dementia 2020 (2015)

2 Popoola A, Keating A, Cassidy E. Alcohol cognitive impairment and the hard to discharge acute hospital inpatients. Ir J Med Sci 2008; 2: 141-5. There is a need to ensure that there is therefore a clear pathway to diagnosis and post-diagnostic support for people in this group.

3 CQC 2017, DAA 2016).

4 Public Health England Guidance – Dementia – Applying all our health 2018

5 Brayne C et al, Dementia before death in ageing societies – the promise of prevention and the reality, PLoS Med 2006;3; 10

6 Dementia UK Update, second edition, Alzheimer's Society, November 2014

7 Public Health England Dementia Profile

8 Etkind, S.N. et al (2017) How many people will need palliative care in 2040? Past trends, future projections and implications for services BMC Medicine 2017 15:102

9 Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040, CPEC and LSE Raphael Wittenberg, Bo Hu, Luis Barraza-Araiza, Amritpal Rehill

10 Alzheimer's Research UK Dementia Statistics Hub

11 The All-Party Parliamentary group (APPG) report 2016 – 'Dementia rarely travels alone:Living with dementia and other conditions'

SEPARATE APPENDICES:-

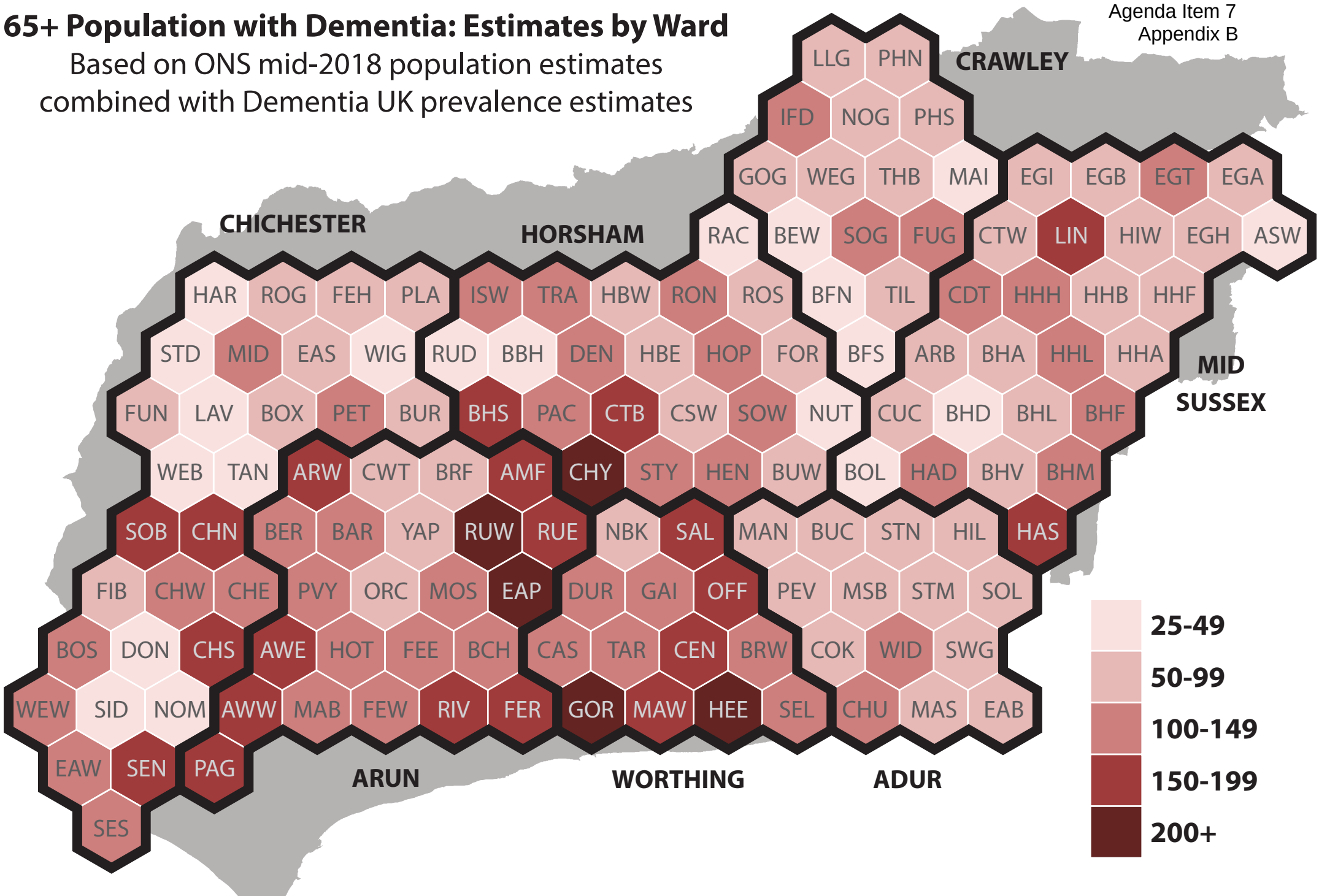
Appendix C - 65+ Population with Dementia: Estimates by Ward

Appendix D – Executive Summary

Appendix E - Delivery Plan (to be ready by spring 2020)

65+ Population with Dementia: Estimates by Ward

Based on ONS mid-2018 population estimates
combined with Dementia UK prevalence estimates



Adur Wards:

BUC	Buckingham
CHU	Churchill
COK	Cokeham
EAB	Eastbrook
HIL	Hillside
MAN	Manor
MAS	Marine (Shoreham)
MSB	Mash Barn
PEV	Peverel
SOL	Southlands
STM	St Mary's
STN	St Nicolas
SWG	Southwick Green
WID	Widewater

Arun Wards:

AMF	Angmering & Findon
ARW	Arundel & Walberton
AWE	Aldwick East
AWW	Aldwick West
BAR	Barnham
BCH	Beach
BER	Bersted
BRF	Brookfield
CWT	Courtwick with Toddington
EAP	East Preston
FEE	Felpham East
FER	Ferring
FEW	Felpham West
HOT	Hotham
MAB	Marine (Bognor)
MOS	Middleton-on-Sea
ORC	Orchard
PAG	Pagham
PVY	Pevensey
RIV	River
RUE	Rustington East
RUW	Rustington West
YAP	Yapton

Chichester Wards:

BOS	Bosham
BOX	Boxfgrove
BUR	Bury
CHE	Chichester East
CHN	Chichester North
CHS	Chichester South
CHW	Chichester West
DON	Donnington
EAS	Easebourne
EAW	East Wittering
FEH	Fernhurst
FIB	Fishbourne
FUN	Funtington
HAR	Harting
LAV	Lavant
MID	Midhurst
NOM	North Mundham
PET	Petworth
PLA	Plaistow
ROG	Rogate
SEN	Selsey North
SES	Selsey South
SID	Sidlesham
SOB	Southbourne
STD	Stedham
TAN	Tangmere
WEB	Westbourne
WEW	West Wittering
WIG	Wisborough Green

Crawley Wards:

BEW	Bewbush
BFN	Broadfield North
BFS	Broadfield South
FUG	Furnace Green
GOG	Gossops Green
IFD	Ifield
LLG	Langley Green
MAI	Maidenbower
NOG	Northgate
PHN	Pound Hill North
PHS	Pound Hill South & Worth
SOG	Southgate
THB	Three Bridges
TIL	Tilgate
WEG	West Green

Horsham Wards:

BBH	Broadbridge Heath
BHS	Billingshurst & Shipley
BUW	Bramber, Upper Beeding & Woodmancote
CHY	Chantry
CSW	Cowfold, Shermanbury & West Grinstead
CTB	Chanctonbury
DEN	Denne
FOR	Forest
HBE	Holbrook East
HBW	Holbrook West
HEN	Henfield
HOP	Horsham Park
ISW	Itchingfield, Slinfold & Warnham
NUT	Nuthurst
PAC	Pulborough & Coldwaltham
RAC	Rusper & Colgate
RON	Roffey North
ROS	Roffey South
RUD	Rudgwick
SOW	Southwater
STY	Steyning
TRA	Trafalgar

Mid Sussex Wards:

ARB	Ardingly & Balcombe
ASW	Ashurst Wood
BHA	Burgess Hill St Andrews
BHD	Burgess Hill Dunstall
BHF	Burgess Hill Franklands
BHL	Burgess Hill Leylands
BHM	Burgess Hill Meeds
BHV	Burgess Hill Victoria
BOL	Bolney
CDT	Crawley Down & Turners Hill
CTW	Copthorne & Worth
CUC	Cuckfield
EGA	East Grinstead Ashplats
EGB	East Grinstead Baldwins
EGH	East Grinstead Herontye
EGI	East Grinstead Imberhorne
EGT	East Grinstead Town
HAD	Hurstpierpoint & Downs
HAS	Hassocks
HHA	Haywards Heath Ashenground
HHB	Haywards Heath Bentswood
HHF	Haywards Heath Franklands
HHH	Haywards Heath Heath
HHL	Haywards Heath Lucastes
HIW	High Weald
LIN	Lindfield

Worthing Wards:

BRW	Broadwater
CAS	Castle
CEN	Central
DUR	Durrington
GAI	Gaisford
GOR	Goring
HEE	Heene
MAW	Marine (Worthing)
NBK	Northbrook
OFF	Offington
SAL	Salvington
SEL	Selden
TAR	Tarring

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West Sussex Joint Dementia Strategy 2020-23 Delivery Plan

Areas	Goals	Actions	By whom
Preventing Well	People live, work and play in environments that promote health and wellbeing and support them to live healthy lives.	1.Explore ways of promoting the NHS Health Check (dementia) leaflet widely. 2.Engage with Long term conditions clinics (i.e. diabetes, hypertension) to explore ways they can be used to identify early signs of dementia. 3.Delivery of lifestyle advice arounda range of risks factors. 4. Deliver Information and advice about weight management. 5. Deliver workplace health offer. 6. Provide Making Every Contact Count' resources and deliver workshops.	Public Health, NHS, Wellbeing programme and wellbeing advisors
	Individuals, families, friends and communities are connected.	1.Explore a Connecting Communities Kite Mark for local businesses. 2. All businesses complete Dementia Friends training. 3. Delivery of social prescribing within GP surgeries.	Public Health, Primary care
	There is greater awareness and understanding of the factors that increase the risk of dementia and how people can reduce their risk by living a healthier life	1.Work with Local Dementia Action Alliances to raise awareness of of the factors that increase the risk of dementia. 2.Increase communications. 3. Raise awareness through commissioned services.	LDAA's, WSCC and CCG comms, commissioners
	Early intervention and ongoing support for hearing and sight loss	1. Hearing tests available at wellbeing events. 2. Explore the viability of a campaign for promoting sight and hearing tests.	Wellbeing hubs, Public Health, Districts & Boroughs
Diagnosing well	People recognise the early signs of dementia. They know what steps to take to receive a diagnosis and the benefits of diagnosis.	1.Facilitate media campaigns particularly around Dementia Action Week 2.Promote Dementia Friends training. 3. Develop a training programme that supports providers in the recognition of the signs of dementia.	WSCC and CCG, Providers, commissioners LDAA's, Dementia Champions
	Improved access to information and advice	1. Explore ways of ensuring information and advice is provided in the right format and is accessible throughout the person's journey and as their needs change.	SPFT, Providers, commissioners, WSCC
Diagnosing well	Improved access to good quality joined up support before and after diagnosis	1. Explore how the referral pathway to support such as Carers Support WS, during the waiting period and post-diagnosis, can be improved.	SPFT, Community & voluntary sector providers, Commissioners
	People have the opportunity to plan for the future along with those around them.	1. Develop a care plan that can be used by the family carer and shared with all those involved in the person's care. The care plan should be holistic and developed with the individiual and their carer. 2. Explore ways of sharing the advance care plan electronically between providers. 3. Look at ways of ensuring there is an easy route back into support if required at any point in the person's journey which could include developing the offer from Proactive care. 4. Explore potential training in care planning and conversations around end of life care.	Commissioners, Primary Care, SPFT, Proactive Care, Ambulance service

Diagnosing well	All groups of people to receive a timely diagnosis including younger people with alcohol related dementia, people with learning disabilities and people from minority groups.	1. Improve recording of ethnicity and sexuality at referral through to diagnosis. 2. Explore training to support sensitive conversations around this topic. 3. Explore ways of ensuring the referral rate for people from BAME groups to reflects the ethnic makeup of that geographic area. 4. Campaign to improve the recruitment and retention of Consultants within the Dementia Assessment Service in Chichester. 5. Clarify the current pathway of diagnosis and post-diagnostic support for people with Alcohol Related Dementia and to agree a map or pathway. 6. Develop, design and deliver a pathway to diagnosis and post-diagnostic support for people with Alcohol Related Dementia. 7. Utilize the DiADem tool to diagnose people in care home settings. 8. GPs and practice nurses to use long term conditions clinics and health campaigns (e.g.: seasonal flu) to consider whether older people at risk of dementia have symptoms that will require further consideration. Communication regarding guide and enagement to all GP practices will be provided. 9. Establish a clear pathway to diagnosis for people with learning disabilities including baseline assessment of functioning. 10. Improve referral routefor people with learning disabilities from Memory	SPFT, Primary care, care providers, acute hospitals, commissioners, community and voluntary sector providers, Community LD team, Health Facilitation team
Supporting well	For people to be enabled to live independently at home	1. Explore ways of promoting the offer of technology that allows people to live at home safely. 2. Work with house planners to see what can be done about ensuring future housing reflects the needs of people with dementia. 3. Procurement of a new care and support at home service that looks to ensure there is sufficient local provision of care and support at home where more support is required. 4. Explore ways of ensuring people with hearing or sight loss have access to regular hearing and sight tests, technological aids, environmental improvements, and accessible information and communications	Commissioners, WSCC Housing planners, Occupational Therapists, Public Health
	For people with dementia to be able to access joined up health and social care and community support throughout the progression of their dementia	1. Work with primary care, hospitals, dementia services and long-term clinics to establish a joined up pathway of support for the patient. 2. Improve access to training/information in Caldicott principles to improve information sharing.	WSCC Learning & Development, Primary Care, SPFT, Alzheimer's Society, acute care, Community & Voluntary sector
	Dementia and carer friendly health and care settings	1. Place based Health and social care providers to conduct dementia friendly environmental audits in buildings accessed by the public. 2. Family carers to be identified and recorded as partners in the care of the person with dementia. 3. Hospitals to promote and reinvigorate the Knowing Me tools. 4. Hospitals to involve patients and family in discharge planning, supporting carers in doing so.	WSCC and CCG, Primary Care, Acute care, Adult Social Care, Care providers, community & voluntary sector providers

Supporting Well	Approaches to care and support that are individual to the person's needs and for the person to be enabled to self manage their dementia and other conditions	1. Care providers to provide care and support in a culturally appropriate manner in order to be accessible to people from BAME and religious minority communities. 2. Commissioners and providers of social and health care to consider the needs of LGB&T+ people when planning and/or running services. 3. Promote life story work in care settings to help the person understand their past experiences.	WSCC Care & Business Support team, Care providers, Commissioners, WSCC Contracts
	Compassionate care and support from staff skilled in dementia	1. Provide a clear offer of education, training and development opportunities for those people and organisations providing care and support for people with dementia at a level that fits with their individual responsibilities. 2. Provide a clear offer of training for workers supporting people with learning disabilities and dementia to ensure they are skilled in supporting someone to remain in their normal care setting for longer following their diagnosis. 3. All health and social care providers to have a framework for dementia training that ensures all staff receive training relevant to their role.	WSCC Learning & Development, Community Dementia Matrons, WSCC Care & Business Support team (CABS), Health & social care providers, Primary Care, Community LD
	For support to be in place to avoid wherever possible unplanned admissions to hospital or inpatient facilities. Where hospital admissions are required, for these to be as short as possible.	1. Develop a care plan that can be used by the family carer and shared with all those involved in the person's care. The care plan should be holistic and developed with the individiual and their carer. 2. Provide training and support to care and nursing homes in managing complex and challenging behaviour and in recognising symptoms that do not need a hospital stay. 3.Explore use of the Enhanced Health in Care Homes Framework. 4. Hospitals to involve patients and family in discharge planning, supporting carers in doing so. 5. To continue to reduce length of stay particularly those longer than 21 days.	Commissioners, Community Dementia Matrons, WSCC Care & Business Support team, WSCC Learning & Development, Acute care
Supporting well	The risk of a Crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined up offer of support	1. Provide a robust offer of information and support for family carers throughout the pathway including an offer of flexible respite. 2. Identify people with dementia and family and friend carers at risk of becoming socially isolated and support them to access their community. 3. Identify ways health, social care and dementia services can work together to support the person and their family at times of crisis.	Commissioners, Adult Social Care, SPFT, Community & Voluntary sector providers, care providers, Community Dementia
	People with dementia and their families have a good experience of support provided by Care Homes and that there is sufficiency of quality, affordable provision within West Sussex that reflects the needs of diverse communities.	1. Care homes have a clear framework of education and training around; identifying the signs of dementia and knowing how to access support, how to avoid an unnecessary hospital admission and leadership. 2. Facilitate a diverse provider care market that can deliver culturally sensitive support and support for people from the LGBT+ community. 3. Work with care and nursing homes to enable them to develop good links into their communities and become part of their local dementia friendly community.	WSCC Learning & Development, WSCC Care & Business Support (CABS), Care providers, WSCC Contracts, commissioners

Living Well	People have access to a range of affordable flexible activities that reflects their interests and needs	1. Provide an offer of services designed to meet the needs of all people with dementia. Services should be inclusive of people from diverse groups. Consideration to be given to the needs of LGB&T+ people and people with sensory impairment. 2. Co-produce an offer of activities with the BAME community. 3. Provide an offer of age appropriate activities for younger people living with dementia. 4. Explore ways of supporting people with dementia to take part in everyday mainstream activities. 5. Provide a seamless offer of support for the person when their needs change or their dementia progresses that includes an element of personal care.	WSCC Day Services, Community & voluntary sector providers, commissioners, care providers
Living Well	There is a whole community response to living well with dementia in safe and enabling communities	1. WSCC, CCG and District & Borough Councils to work together to explore ways the Local Dementia Friendly Community Groups can become sustainable. This includes how they are supported and funded. 2. Support the development of new Dementia Friendly Community Groups. 3. Public sector organisations to become dementia friendly organisations including the use of Dementia Champions in all departments delivering dementia friends training. 4. Place based Health and social care providers to conduct dementia friendly environmental audits in buildings accessed by the public. 5. There is a proactive approach from services such as Fire, Police and Trading Standards that supports people living with dementia to live safely in their communities. 6. Community transport plan. 7. Work with WSCC community planning to provide dementia friendly environments. 8. Improve links to Dementia Champions in delivering dementia friends training. 9. Improve links between Local Dementia Action Alliances and Wellbeing hubs to better promote local activities	WSCC, CCG, District & Boroughs, WSCC Transport, Fire & Rescue, Trading Standards, voluntary and community providers
	People can maintain and develop their relationships and be able to contribute to their community	1. There is a clear offer of support for people affected by dementia to be enabled to maintain and develop social connections through peer support, carers groups and similar initiatives to help build resilience. 2. There is a clear offer of practical and emotional support for family members and dependent children of people with Early Onset Dementia. 3. There is an offer of support for people with dementia and family and friend carers to take part in paid and unpaid work.	Community and voluntary sector providers, WSCC & CCG Commissioners
Living Well	Carers of people with dementia are able to access information, support as needed and feel able to continue with their caring role	1. Providers identify and record family and friend carers and treat them as partners in the care of the person with dementia. 2. Carers are offered an assessment of their own needs and have access to psychological therapies. 3. Explore ways of ensuring there is a well coordinated approach to information and advice where a similar level and quality of information can be accessed through all information providers. 4. Provide an offer of education and training for family carers that helps them to build up an individual strategy for supporting the person they care for. Training to be provided in a format that is right for them and at a time that is suitable for them. 5. CRISP and similar training for carers to be promoted. 6. Provide a offer of flexible respite. 7. Promote the Short breaks offer for carer. 8. Support the carer to pursue activities individual to them including paid and unpaid work.	Commissioners, Community & Voluntary Sector providers, Primary Care, Acute care, care providers

Dying Well	There is support for people to die with dignity in a place of their choice	1. All health and social care providers to be trained in completing advance care plans and the sensitivities around these conversations. 2. Explore ways of sharing the advance care plan electronically between providers.	Health and social care providers, commissioners, Ambulance
	People with dementia approaching the end of life, should experience high quality, compassionate and joined-up care	1. Provide a training framework to ensure there is a workforce across the dementia care system that has the right skills, behaviours and values to support people living with dementia in the end stages of life and is equipped to do so. 2. Provide training and support to care and nursing homes in managing end of life care in people with dementia and in recognising symptoms that do not need a hospital stay.	WSCC learning & development, WSCC Care & Business Support (CABS), Care providers, WSCC Contracts, commissioners, Acute care, Ambulance service, SPFT, hospices
Dying Well	Families and carers are provided with timely co-ordinated support before death, at the time of death and bereavement	1. Improve access to training/information in Caldicott principles to improve information sharing amongst all providers involved in the end of life stage. This should extend to ensuring the family understands what is happening and are updated regularly. 2. Families and carers are offered bereavement support at a time that is right of the them.	Commissioners, Community & Voluntary Sector providers, Adult Social care, Ambulance service, SPFT, Acute care, hospices, primary care

Suggested initiatives for the future

The following initiatives look at what might be achieved if there was some additional funding available in the future.

Outcome	Objective/Action	Measurements (to be further developed)
Minority Groups	Funded community champions and project workers	Role spec, Role Objectives, Appraisal and individual local KPI's Increased diagnosis rates for BAME. Increase in number of carers assessments
	Training and education for community champions	Evidence of training completed and put into practice Increased diagnosis rates for BAME. Increase in number of carers assessments
	Co-production with people from BAME communities	X no. of focus groups per annum and number of people involved. Increased diagnosis rates for BAME. Increase in number of carers assessments
	Faith groups holding their own funding pot.	Criteria and outcomes and KPI's set and monitored. Increased diagnosis rates for BAME. Increase in number of carers assessments
	Embassy links and celebrity endorsements.	Increased diagnosis rates for BAME. Increase in number of carers assessments and registrations with Carers Support WS.
Dementia Friendly Communities	Develop a business case for sustainining the work of the Local Dementia Friendly Communities Groups	Increase in number of dementia friends and dementia friendly organisations
		Long term increase in diagnosis rate.
		Increase in number of carers assessments and registrations with Carers Support WS.
		Growth in number and reach of Local Dementia Friendly Community Groups particularly into more rural areas.
	Facilitate shared learning across Local Dementia Action Alliances	As above
	Increase number of dementia friends by 1% increase which potentially equates to 2,000 dementia friends per year.	As above
	Annual conference for Local Alliance leads to share knowledge, grow and network and annual local events.	As above
	Support with comms, social media and dementia website(s)	As above
		Increase engagement and comms by x%
	2 funded f/t co-ordinators for Local Alliances	A measurement tool which could sit alongside the Wellbeing Indicators (developed in conjunction with Public Health)
	Funding all Local Alliance leads.	A measurement tool which could sit alongside the Wellbeing Indicators (developed in conjunction with Public Health)
		Growth in number and reach of Local Dementia Friendly Community Groups particularly into more rural areas.
	Individual funding pot for each Local Alliance for pop up events, training, education and comms.	Work with Public Health to develop a measurement tool which could sit alongside the Wellbeing Indicators.
		Growth in number and reach of Local Dementia Friendly Community Groups particularly into more rural areas.
	Training for volunteers and communities.	Work with Public Health to develop a measurement tool which could sit alongside the Wellbeing Indicators.
		Growth in number and reach of Local Dementia Friendly Community Groups particularly into more rural areas.

Support for family and friend carers and meangful day activities	Commission Immersive training for care staff such as the 'Dementia Tour'.	Nos. using training.
		Reduction in unplanned admissions to hospital for the individual care home.
		Fewer referrals to the DCS from the individual care home.
	Training and education for GP's and Primary Care Networks including 'Top Tips' for GP's tool.	Nos. using training.
		Reduction in unplanned admissions to hospital for the individual care home.
		Fewer referrals to the DCS from the individual care home.
	One stop shops in the north and south of West Sussex that provides information, advice and support for people with dementia and their families and carers based on the Dementia Support/Sage House model.	Usage.
		More joined up support for people as their dementia progresses.
		Fewer referrals to secondary care services such as Living Well with Dementia and Dementia Crisis Service.
	Mapping services to identify gaps and linking people into support.	More joined up support for people as their dementia progresses.
	Central database of all services/activities.	Fewer referrals to secondary care services such as Living Well with Dementia and Dementia Crisis Service.
	Website such as Dementia Roadmap	Reduction in unplanned admissions to hospital for the individual care home.
	Commissioning 'Keeping In Touch' Programme (Alzheimer's Society).	Fewer referrals to secondary care services such as Living Well with Dementia and Dementia Crisis Service.
		Reduction in unplanned admissions to hospital for the individual care home.
		More joined up support for people as their dementia progresses.
		A measurement tool designed with Public Health to measure distance travelled.
	Weekend away breaks for people with dementia and their family carer. Either fully costed or with a financial contribution from the service user.	Usage/Uptake. A measurement tool designed with Public Health to measure distance travelled. Evaluation report.
	Personal care support within Short Breaks service.	Improved customer experience
	Use Crossroads Emergency Care service for ad-hoc needs.	Improved customer experience

Dementia & Learning Disabilities	Training and education around prescribing	Clearer more robust pathway for people with learning disabilities
	Baselining for people with Downs Syndrome from age 30	Early detection and diagnosis fo dementia for people with Downs Syndrome
	Baselining for all people with learning disabilities not just people with Downs Syndrome	Early detection and diagnosis for all people with learning disabilities
	Commission a severe LD specialist to support diagnosis in MAS.	Improved customer experience and early diagnosis
	Upskill Proactive Care to provide support for people with LD and dementia.	Improved customer experience

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