

The Pan Sussex Integrated End of Life and Dementia Care Pathway has been developed through multi-agency and multi-disciplinary stakeholder group collaboration across Sussex as part of the End of Life Care in Dementia Regional Innovation Funded project for NHS Sussex.

The pathway comprises six phases:

1. Recognising there is a problem (awareness)
2. Discovering that the condition is dementia (assessment, diagnosis and involving the person with dementia in planning for their future care)
3. Living well with dementia (maximising function and capacity to enhance wellbeing and planning for the future including end of life)
4. Getting the right help at the right time (accessing appropriate and timely support. Reviewing advance care plans)
5. Nearing the end of life, including the last days of life (palliative care and ensuing advance care plans are reviewed and respected)
6. Care after death (supporting relatives and carers to maintain wellbeing)

Each phase identifies what people with dementia, relatives and carers need; what support is available in Sussex to support those needs and what needs to happen to ensure that the support available meets those needs.

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Through this process the knowledge and skills required by health and social care practitioners to successfully deliver the integrated dementia care pathway have also been identified as well as the information needs of people with dementia, relatives and carers.

The core document is being used to develop:

- flow diagrams to provide an easily accessible guide to the pathway for practitioners
- an information leaflet for people with dementia their relatives and carers will describe the pathway, what information and support to expect at each phase

The Pan Sussex Integrated End of Life and Dementia Care Pathway

Phase 1	Phase 2	Phase 3	Phase 4	Phase 5	Phase 6
Recognising there is a problem	Discovering that the condition is Dementia	Living Well with Dementia	Getting the right help at the right time	Nearing the end of life including care in the last days of life	Care after death



Phase 1	Phase 2	Phase 3	Phase 4	Phase 5	Phase 6
Recognising there is a problem	Discovering that the condition is Dementia	Living Well with Dementia	Getting the right help at the right time	Nearing the end of life including care in the last days of life	Care after death

Phase 1 Recognising there is a problem		
NEEDS of people with dementia, their relatives and carers	SUPPORT available	What needs to HAPPEN for support to meet needs
<p>Greater general public awareness & education regarding dementia (signs, types and ways to live well) to remove stigma and normalise dementia so people feel able to seek advice earlier in the knowledge they will be taken seriously and their concerns listened to and acted upon.</p> <p>Widely available information easy to access, clear, factual, practical & prompts people to seek help</p> <p>One point of contact to provide consistent advice & guidance</p> <p>Knowledgeable and supportive professionals who recognise the signs and symptoms of dementia, including those of early onset, the needs of the relatives/carers, and can signpost to other appropriate support services</p> <p>Access to timely assessment and diagnosis with no avoidable delays</p> <p>Support & contact through whole process including pre-diagnosis for person, their relatives/carers</p> <p>Access to support & dementia education to empower people to be as independent as possible & fully involved in decision making</p>	<p>Person's own networks i.e. family, friends, neighbours, employers; housing providers; wider society and/or community they have regular contact with,</p> <p>Health & Social Care professionals they have contact with</p> <p>Primary Care: General Practitioner, Integrated Primary Care Team (IPCT) or Neighbourhood Support Team (NST)</p> <p>Secondary Care: Acute hospitals</p> <p>Information sources e.g. leaflets; internet; media & media campaigns; the NHS Choice; The Alzheimer's Society; Age UK; Carers Centres and organisations</p>	<p>Increased public & professional awareness of dementia through wider availability of clear & concise information about dementia</p> <p>Increased knowledge, skills & awareness of directly involved professionals of the integrated dementia care pathway: how to access information & support, to improve signposting & consistency of service</p> <p>Shift in culture and attitude (clinicians & public) to one of positive management of condition & understanding impact of dementia</p> <p>Robust assessment system – including single point of access e.g. a dementia information/helpline line</p> <p>Counselling offered early to person with dementia, relatives and carers</p> <p>Early & timely access & referral to services to support relatives / carers</p> <p>Recognition of relative/carer as partner in care by professionals</p> <p>Offer routine dementia screening for over 60s</p> <p>Within Learning Disability - assessing/ identifying or diagnosing early to establish a baseline as benchmark for ongoing assessment</p>

Phase 1 Recognising there is a problem	Phase 2 Discovering that the condition is Dementia	Phase 3 Living Well with Dementia	Phase 4 Getting the right help at the right time	Phase 5 Nearing the end of life including care in the last days of life	Phase 6 Care after death
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Phase 2 Discovering that the condition is Dementia		
NEEDS of people with dementia, their relatives and carers	SUPPORT available	What needs to HAPPEN for support to meet needs
<p>Timely access to specialist assessment & diagnosis</p> <p>Honest & effective communication of diagnosis, prognosis & time to absorb & discuss implications e.g. treatment options, legal considerations; planning future care</p> <p>Professionals have positive approach to future & focus on persons' abilities (assets)</p> <p>To be empowered & retain control via access to relevant information & support to be make own choices</p> <p>Appropriate signposting & referral to enable the person to 'live well with dementia' and maximise their independence.</p> <p>Appropriate information sharing by professionals to improve communication & response times</p> <p>A 'What Next?' information pack – signposting to support services, etc</p> <p>Access to ongoing, appropriate specialist support for treatment / medication etc</p> <p>Single source of ongoing support</p> <p>Access to Carer Assessment & support</p> <p>Option for genetic counselling</p>	<p>Initial Assessment by GP, Health & Social Care professionals or acute hospital</p> <p>Referral to Memory Assessment Service (MAS) for assessment by Multi-Disciplinary Team</p> <p>MAS Dementia Advisors /support workers</p> <p>GP, IPCT/ NST Geriatricians & other healthcare specialists</p> <p>Living Well with Dementia Team / Community Mental Health Team/Community Psychiatric Nurses</p> <p>Adult Social Care</p> <p>Outreach services e.g. for BME, LGBT groups</p> <p>Community Learning Disability Team (CLDT)</p> <p>Alzheimer's Society</p> <p>Dementia UK Admiral Nurses</p> <p>Age UK</p> <p>Acute Hospitals Dementia Champions</p> <p>Counsellors</p> <p>Lawyers & Citizen's Advice re: Lasting Power of Attorney, Wills; employment rights etc</p> <p>Department of Work & Pensions (DWP)</p> <p>Local Community groups</p> <p>'ROCK' – website http://www.sussexpartnership.nhs.uk/service-users/wellbeing/rock</p>	<p>Increase professionals awareness & understanding of available sources of support, improve signposting & access to medication & treatment</p> <p>Requirement for referral to MAS confirm diagnosis</p> <p>Access to counselling for person with dementia</p> <p>Timely access to carers assessment</p> <p>Improved shared information systems across agencies</p> <p>Allocated Key worker e.g. dementia adviser</p> <p>Support from appropriate professionals</p> <p>'One stop shop' / specialist centre for holistic dementia care</p> <p>Comprehensive, timely & accurate information e.g. a "Check list"</p> <p>Post diagnostic review to ensure person/carers has understood diagnosis</p> <p>Place on dementia or Long Term Conditions Register</p> <p>Initiate Advanced Care Planning to facilitate choices</p> <p>Use professional patient /carer as means of support</p>

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Phase 3 Living Well with Dementia		
NEEDS of people with dementia, their relatives and carers	SUPPORT available	What needs to HAPPEN for support to meet needs
<p>Holistic assessment of needs & circumstances</p> <p>Coordinated services</p> <p>Regular, open, honest communication</p> <p>Opportunities to talk about concerns & future plans</p> <p>Advice & support to enable person to 'live well'</p> <p>Support from professionals to start future planning earlier e.g. ACP*, ADRT** LPAs***</p> <p>Screening & management of other health conditions</p> <p>Early intervention to resolve issues & enable person to continue 'living well'</p> <p>Timely access to treatment / medication to maintain optimum function</p> <p>Legal & financial advice for now & future</p> <p>Dementia education for person, relative(s) / carers</p> <p>Opportunity to record life story 'This is Me' etc</p> <p>Knowledgeable & skilled named worker to support, navigate, coordinate, provide continuity & plan</p> <p>Access to employment / education for person & carer</p>	<p>Own networks - Family, friends, neighbours, community, local clubs & social activities</p> <p>Primary Care -G.P/ IPCT /NST Community Nurse/ Social Worker; other supporting health & social care professionals</p> <p>Memory Assessment Service support, care, treatment, review – signposting to other services. Regular multidisciplinary review with key worker & others (may change during different stages).</p> <p>Proactive Care Services</p> <p>Adult Social Care – support & access to Personal Budget</p> <p>Complimentary therapists</p> <p>Housing providers e.g. housing associations; landlords; sheltered & extra-care; Telecare</p> <p>Living Well with Dementia Team / Community Mental Health Team/Community Psychiatric Nurses Community Learning Disability Team (CLDT)</p> <p>Dementia Specialist Nurse / Admiral Nurse</p> <p>Crisis /emergency support & advice e.g. Out of Hours Doctor Service (OOH) / One Call & Rapid Assessment & Intervention Team</p>	<p>Advance Care Planning is a routine practice e.g. included in annual dementia review by GP</p> <p>Well written, easy to follow information with contacts</p> <p>Regular holistic wellbeing check involving relatives /carers & providing information to maintain optimum physical health</p> <p>Primary Care / GP clinics to monitor & promote health & wellbeing & healthy diet to optimise brain function</p> <p>Professionals to encourage people to talk & ask questions</p> <p>Helpline</p> <p>Forum to share strategies & ideas developed by carers</p> <p>One contact point to improve co-ordinated response</p> <p>Effective & efficient communication & information sharing between services</p> <p>Information available in different formats</p> <p>Involving next of kin / carer</p> <p>Support to relatives/carers access information & resources</p> <p>Access to services based on need not labels</p>

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Phase 3 Living Well with Dementia		
NEEDS of people with dementia, their relatives and carers	SUPPORT available	What needs to HAPPEN for support to meet needs
<p>Timely access to Carers Assessments & referral for to carers support services</p> <p>Appropriate, timely advice & access to benefits</p> <p>Professionals to know appropriate advice sources</p> <p>Support for person, relative(s)/carers to deal with emotional impact of diagnosis & plans for future</p> <p>Relatives /carers to know signs of deterioration & where to seek help & advice</p> <p>Culturally sensitive services</p> <p>Dementia friendly communities (incl. legal services & banks regarding LPAs^{***})</p> <p>Ease of access to range of integrated services to retain choices & control of their life</p> <p>Flexible approach supporting people with dementia in acute hospitals</p> <p>Rapid access to emergency / crisis support</p>	<p>Dementia CRISIS Team / South East Coast Ambulance Service (SECAmb) /Acute hospitals</p> <p>Managing legal affairs - Lawyer & Office of Public Guardian</p> <p>Dementia friendly communities</p> <p>Support groups for people with dementia & their families e.g. Alzheimer’s Society / Age UK / Voluntary organisations and Charities/Day Care Services /Activity & Lunch Clubs / Specialist groups /clubs / Advocacy Services / Mediation Services</p> <p>Residential Care & Nursing Homes / Domiciliary Care</p> <p>Carers Support Services</p> <p>Hospice @ Home</p> <p>Benefits Advice – to access appropriate benefits as well as debt counselling etc</p> <p>Department of Work & Pensions (DWP)</p> <p>Completing a ‘This is Me/This is About me’ document and ensuing copy is kept and transferred with person between services</p> <p>Specialist medical services e.g. incontinence service, optician, dentist</p>	<p>Encourage & support completion of ‘This is Me’ or equivalent</p> <p>This is Me Bag made available to store important information</p> <p>Access to high quality respite care</p> <p>Dementia friendly communities</p> <p>Consistent emergency out of hours support</p> <p>Appropriate safeguarding processes in place</p>

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*ACP – Advance Care Plan ** ADRT – Advance Directive to Refuse Treatment *** LPA – Lasting Power of Attorney

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Phase 4 Getting the right help at the right time		
NEEDS of people with dementia, their relatives and carers	SUPPORT available	What needs to HAPPEN for support to meet needs
<p>Personalised & crisis plans for timely & appropriate, 24/7 support</p> <p>Rapid access to services to avoid crises e.g. timely referral to specialists</p> <p>Prompt responses in crisis</p> <p>Professionals who understands person & family /carers needs & limitations, listens & includes</p> <p>Opportunities to review Advance Care Plan</p> <p>Education of relatives/ carers to recognise changes/ deterioration / end of life</p> <p>Knowledgeable & skilled named worker to support, navigate, coordinate, provide continuity & plan</p> <p>Regular wellbeing reviews to identify change/deterioration</p> <p>Access to holistic assessment, care & treatment / multi-disciplinary team and/or specialist interventions</p> <p>Prompt access to services & information in a crisis</p> <p>Timely information to support future planning</p>	<p>Support wellbeing & decision making in person’s best interests - early involvement & information about what is helpful</p> <p>Own networks - Family, friends, neighbours, community, local clubs & social activities</p> <p>Primary Care -G.P/ IPCT /NST /Community Nurse/ Social Worker; other supporting health & social care professionals</p> <p>Proactive Care Services</p> <p>Continuing Health Care Assessment & Funding</p> <p>Adult Social Care – support & access to Personal Budget</p> <p>Complimentary therapists</p> <p>Housing providers e.g. housing associations; landlords; sheltered & extra-care; Telecare</p> <p>Living Well with Dementia Team / Community Mental Health Team/Community Psychiatric Nurses/ Community Learning Disability Team (CLDT)</p> <p>Dementia Specialist Nurse / Admiral Nurse</p> <p>Crisis /emergency support & advice e.g. Out of Hours Doctor Service (OOH) / One Call / Rapid Assessment & Intervention Team /</p>	<p>Different specialists provide right care, right time, right support a) Advance Care Planning b) Contingency / alternatives knowing options & contacts</p> <p>Listening to the person with dementia, relatives/ carers treating as ‘partners in their care’</p> <p>Training to improve practitioner knowledge, understanding & skills (including decision making skills) of support services available</p> <p>Information available in different formats</p> <p>Access to appropriate advocacy support</p> <p>Normalising life e.g. socialising and enjoying life</p> <p>Support services available 24/7 - a Sussex helpline?</p> <p>Increased use of technology to support independence e.g. sensor mats; alarms</p> <p>Access to specialist practitioners e.g. Psychiatrist/ IPCT/ NST</p> <p>Annual Wellbeing checks</p> <p>Specialist & ‘dementia friendly’ wards/ units in general hospitals</p>

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Phase 4 Getting the right help at the right time		
NEEDS of people with dementia, their relatives and carers	SUPPORT available	What needs to HAPPEN for support to meet needs
<p>Access to appropriate rolling respite, home support, day care / activities to support family/carer wellbeing</p> <p>Information regarding appointments etc to be sent to family/carer</p> <p>Support to access to benefits etc</p> <p>Prompt access to additional funding e.g. Continuing Health Care (CHC) for end of life care</p> <p>Access to Carers groups to support relatives and carers</p>	<p>Dementia CRISIS Team / SECamb / Acute hospitals</p> <p>Dementia friendly communities</p> <p>Support groups for people with dementia & their families e.g. Alzheimer’s Society / Age UK / Voluntary organisations/visiting service & Charities /Day Care Services /Activity & Lunch Clubs / Specialist groups /clubs / Advocacy Services / Mediation Services /Samaritans</p> <p>Residential Care & Nursing Homes / Domiciliary Care</p> <p>Carers Support Services</p> <p>Hospice @ Home</p> <p>Benefits Advice, DWP Lawyer & Office of Public Guardian</p> <p>Specialist medical services e.g. incontinence service, optician, dentist</p>	<p>Carers centre & carers forum</p> <p>GP surgeries with touch screen to access websites & someone to help</p> <p>Empowering relatives and carers through education & information to recognise needs and access support</p> <p>Improve information to raise awareness of support available</p> <p>Advance Care Planning is routinely completed upon admission to residential / nursing care homes</p>

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Phase 5 Nearing the end of life including care in the last days of life		
NEEDS of people with dementia, their relatives and carers	SUPPORT available	What needs to HAPPEN for support to meet needs
<p>Early planning to maximise possibility of person being supported in their preferred place of care</p> <p>Information & education for family/carers & professionals about last stages of life</p> <p>Professionals who understand & respond to the persons' priorities, wishes & cultural needs</p> <p>Review of & respect for, wishes stated in ACP; ADRT etc & support to implement</p> <p>Treated with dignity & respect & according to the persons' expressed wishes</p> <p>Knowledgeable & skilled named worker to support, navigate, coordinate, provide continuity & plan</p> <p>Continuity of medical, social, spiritual, emotional & practical care & support for the person, family /carer & which facilitates the persons preferences & choices</p> <p>Access to good quality end of life care/ palliative care including symptom control</p> <p>Access to counselling for family/carers if appropriate</p> <p>Pre-bereavement care for family/carers</p>	<p>Support to die in preferred place of care through own networks – family, carers etc</p> <p>Primary Care -G.P/ IPCT /NST /Community Nurse/ Social Worker; other supporting health & social care professionals</p> <p>Health condition monitored & reviewed through GP's End of Life Care register & gold Standards Framework meetings & Liverpool Care Pathway</p> <p>Proactive Care Services</p> <p>Continuing Health Care Assessment & Funding</p> <p>Adult Social Care – support & access to Personal Budget</p> <p>Complimentary therapists</p> <p>Residential Care & Nursing Homes / Domiciliary Care</p> <p>Carers Support Services</p> <p>Hospice @ Home</p> <p>Review of Advance Care Plans Advance Decisions to refuse treatment (ADRT)/ DNACPR by G.P. & IPCT/NST</p> <p>Holistic support from Hospice @ Home, Hospice Multi Disciplinary Team 'Just in Case Medications', Advanced Care Nurse Practitioners, MacMillan Community Team Integrated Night Sitting Service, End of life co-ordinators & equipment</p>	<p>Improve professionals ability to recognising "Dying Phase"</p> <p>Continuity of care through care journey with named healthcare professional with defined responsibility for communicating changes to all involved & who coordinates ACP/ADRT/DNACPR</p> <p>All professionals understand persons' emotional & spiritual needs & who to contact for specialist emotional support</p> <p>Review of ACP / LPA / ADRT /DNACPR & preferred place of care (PPC) & implemented according to person's wishes</p> <p>Hospitals discharge people with clear care advice, information & contact details</p> <p>Timely assessment & response for Continuing Care Funding (CHC) to ensure appropriate / increased support to reduce fear of inadequate access to appropriate end of life care</p> <p>Improve access to specialist services & equipment</p> <p>Access to information , appropriate support & services</p> <p>Retaining GP's in nursing homes</p>

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Phase 5 Nearing the end of life including care in the last days of life		
NEEDS of people with dementia, their relatives and carers	SUPPORT available	What needs to HAPPEN for support to meet needs
Dying with dignity in place of choice	<p>Spiritual support from local churches/faith support</p> <p>Community Learning Disability Team (CLDT)</p> <p>Dementia Specialist Nurse / Admiral Nurse</p> <p>Crisis /emergency support & advice e.g. Out of Hours Doctor Service (OOH) / One Call / Rapid Assessment & Intervention Team / Dementia CRISIS Team / SECamb / Acute hospitals</p>	<p>Co-ordinated Teamwork with all services involved</p> <p>Access to EOLC Support/Adviser – EOLC register and discussion at Gold Standard framework meetings (GSF)</p> <p>Emotional and Social support for carers e.g. Pre death course; pre bereavement support (including counselling)</p> <p>Implement Liverpool Care Pathway (LCP) as required</p> <p>Family/carers to review funeral arrangements /support options</p>

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Phase 6 Care after death		
NEEDS of people with dementia, their relatives and carers	SUPPORT available	What needs to HAPPEN for support to meet needs
<p>Recognition that the end of life does not stop at the point of death</p> <p>Ensuing person's wishes are respected regarding care after death</p> <p>Empathic support for family & carer including timely verification of death; out of hours support - emotional, spiritual, practical care & bereavement support with opportunities to talk & grieve</p> <p>Sensitive post bereavement support –especially important if there are issues regarding carrying out individuals wishes</p> <p>Information & practical support regarding registering death; financial affairs; who needs to be notified & post bereavement support</p> <p>Named person to continue family/carers support for a period of time</p> <p>Access to counselling if appropriate</p> <p>One central contact point & information shared by all professionals</p> <p>Support & information about bereavement support</p>	<p>Bereavement & practical support through family, friends G.P. & IPCT/NST</p> <p>Hospice @ Home Hospice Bereavement Team</p> <p>Dementia Specialist Nurse / Admiral Nurse / Advanced Care Nurse Practitioners/ Community Learning Disability Team (CLDT)</p> <p>Support within community</p> <p>Spiritual support of their choosing;</p> <p>Carers Support Groups</p> <p>Local bereavement support groups e.g. run by religious & voluntary groups</p> <p>CRUSE</p> <p>Admiral Nurse support</p> <p>Practical support with financial arrangements from: DWP Bereavement Service Funeral Directors Carers Centre Samaritans</p>	<p>Family/carers encouraged to use bereavement services & care at point of death</p> <p>Support available to help with practical arrangements</p> <p>Recognition that both relatives & practitioners may require 'closure' & facilitating this</p> <p>Funding for carer groups to recognise need for post bereavement support e.g. Bereavement care – new beginning course - need to include in prospectus funding</p> <p>Identifying the carer and their role – financial, social, psychological</p> <p>Timely & appropriate referral to services e.g. counselling/ support groups</p> <p>Care co-ordinator to follow up relatives/ carer - Carers groups – ongoing support / counselling</p>