Appendix 1b Pathway

Pan Sussex Integrated End of Life and Dementia Care Pathway January 2013

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 and planning for the future to enhance wellbeing)
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.

Through this process the knowledge and skills required by health and social care practitioners to successful 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
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. **Widely** available information easy to access, clear, factual, practical & prompts people to seek help **One** point of contact to provide consistent advice & guidance **Knowledgeable** and supportive professionals who recognise the signs and symptoms of dementia, including those of early onset, the needs of the relatives /carers, significant others and can signpost to other appropriate support services **Access** to timely assessment and diagnosis with no avoidable delays **Support** & contact through whole process including pre-diagnosis for person, relatives /carers / significant others **Access** to support & dementia education to empower people to be as independent as possible & fully involved in decision making	**Person's** own networks i.e. family, friends, significant others, neighbours, employers; housing providers; wider society and/or community they have regular contact with, **Health** & Social Care professionals they have contact with **Primary** Care: General Practitioner, Integrated Primary Care Team (IPCT) or Neighbourhood Support Team (NST) **Secondary Care:** Acute hospitals **Information** sources e.g. leaflets; internet; media & media campaigns; the NHS Choice; The Alzheimer's Society; Age UK; Carers Centres and organisations	**Increased** public & professional awareness of dementia through wider availability of clear & concise information about dementia **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 **Shift** in culture and attitude (clinicians & public) to one of positive management of condition & understanding impact of dementia **Robust assessment system** – including single point of access e.g. a dementia information/helpline line **Counselling** offered early to person with dementia, relatives and carers **Early** & timely access & referral to services to support relatives / carers / significant others **Recognition** by professionals of relative/carer / significant others as partner in care **Offer** routine dementia screening for over 60s **Within** Learning Disability – early assessment /diagnosis to establish baseline as benchmark for ongoing care

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

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

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

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

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

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 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**
Access to appropriate rolling respite, home support, day care / activities to support family/carer wellbeing **Information** regarding appointments etc to be sent to family/carer **Support** to access to benefits etc **Prompt** access to additional funding e.g. Continuing Heath Care (CHC)for end of life care **Access** to Carers groups to support relatives and carers	Dementia CRISIS Team / SECAmb / Acute hospitals **Dementia** friendly communities **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 **Residential** Care & Nursing Homes / Domiciliary Care **Carers** Support Services **Hospice** @ Home **Benefits Advice**, DWP Lawyer & Office of Public Guardian **Specialist** medical services e.g. incontinence service, optician, dentist	**Carers** centre & carers forum **GP** surgeries with touch screen to access websites & someone to help **Empowering** relatives and carers through education & information to recognise needs and access support **Improve** information to raise awareness of support available **Advance** Care Planning is routinely completed upon admission to residential / nursing care homes

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 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**
Early planning to maximise possibility of person being supported in their preferred place of care **Information** & education for family/carers / significant others & professionals about last stages of life **Professionals** who understand & respond to the persons' priorities, wishes & cultural needs **Review** of & respect for, wishes stated in ACP; ADRT etc & support to implement **Treated** with dignity & respect & according to the persons' expressed wishes **Knowledgeable** & skilled named worker to support, navigate, coordinate, provide continuity & plan **Continuity** of medical, social, spiritual, emotional & practical care & support for the person, family /carer / significant others & which facilitates the persons preferences & choices **Access** to good quality end of life care/ palliative care including symptom control **Access** to counselling for family/carers/ significant others if appropriate **Pre-bereavement** care for	**Support** to die in preferred place of care through own networks – family, carers etc **Primary** Care -G.P/ IPCT /NST /Community Nurse/ Social Worker; other supporting health & social care professionals **Health** condition monitored & reviewed through GP's End of Life Care register & Gold Standards Framework meetings **Proactive** Care Services **Continuing** Health Care Assessment & Funding **Adult** Social Care – support & access to Personal Budget **Complimentary** therapists **Residential** Care & Nursing Homes / Domiciliary Care **Carers** Support Services **Hospice** @ Home **Review** of Advance Care Plans Advance Decisions to refuse treatment (ADRT)/ DNACPR by G.P. & IPCT/NST **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	**Improve** professionals ability to recognise the normal "Dying Phase" **Continuity** of care through care journey with named healthcare professional with defined responsibility for communicating changes to all involved & who coordinates ACP/ADRT/DNACPR **All** professionals understand persons' emotional & spiritual needs & who to contact for specialist emotional support **Review** of ACP / LPA / ADRT /DNACPR & preferred place of care (PPC) & implemented according to person's wishes **Hospitals** discharge people with clear care advice, information & contact details **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 **Improve** access to specialist services & equipment **Access** to information, appropriate support / services **Retaining** GP's in nursing homes

family/carer / significant others		

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 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	**Spiritual** support from local churches/faith support **Community** Learning Disability Team (CLDT) **Dementia** Specialist Nurse / Admiral Nurse **Crisis** /emergency support & advice e.g. Out of Hours Doctor Service (OOH) / One Call / Rapid Assessment & Intervention Team / Dementia CRISIS Team / SECAmb / Acute hospitals	**Co-ordinated** Teamwork with all services involved **Access** to EOLC Support/Adviser – EOLC register and discussion at Gold Standard framework meetings (GSF) **Emotional** and Social support for family/ carers / significant others e.g. Pre death course; pre bereavement support (including counselling) **Family/carers/** significant others to review funeral arrangements /support options

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