Appendix 1a Summary

Pan Sussex Integrated End of Life and Dementia Care Pathway 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 to enhance wellbeing and planning for future care 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 ensuring 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 that and what has to happen to ensure that the support available meets those needs.

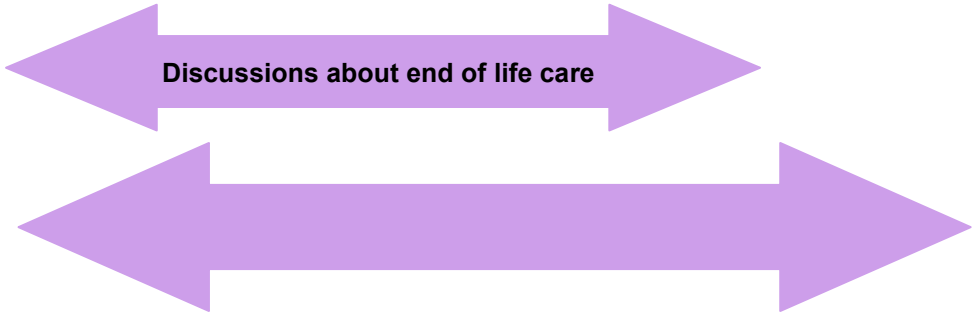
Through this process the knowledge and skills required by health and social care practitioners to successfully deliver the integrated dementia care pathway have been identified, alongside the information needs of people with dementia, their relatives and carers.

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 that will describe the pathway and explain 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**



Co-ordination, monitoring and reviewing care and support

Phases		Key Activities for Practitioners
1	**Recognising there is a problem**	**Ensure** information is available to help people to recognise and understand dementia and know what support and options are available **Raise** dementia awareness / education through patient participation groups community groups etc **Involve** others to create dementia friendly communities **Work** to shift the culture and attitudes of both the public and practitioners to one of positive management of the condition and an understanding of the impact of dementia on individuals, their relatives and carers
2	**Discovering that the condition is Dementia**	**Refer** to Memory Assessment Services for early diagnosis & support **Timely** access to information, advice and support (post diagnosis/on-going) **Recognise** and support the information needs of relatives / carers including understanding dementia, impact on daily living and options available **Initiate** a conversation regarding living well and planning future care **Recognise** and support the person's spiritual and cultural needs
3	**Living Well with Dementia**	**Work** with the person, relatives / carers / significant others to support continued wellbeing, promote an active life and inclusion **Include** on Dementia Register to ensure regular monitoring and review **Initiate /review** Advance Care Plan (ACP) discussion in annual dementia review **Be alert** to prompts and cues to initiate *Conversations for Life* (ACP) **Support** completion of *'This is Me'* (or equivalent); give '*This is Me Bag*' to assist communication, understanding and support given **Timely** access to information, advice e.g. benefits, activities, care, respite etc **Normalise** dementia, promote inclusion, awareness and understanding **Recognise** and support person's spiritual and cultural needs
4	**Getting the Right Help at the Right Time**	**Review** ACP /Advance Directive to Refuse Treatment regularly and prior to any intervention **Contingency** plans in place to manage unexpected deterioration **Timely** and appropriate referral to specialists as need arises **Assess** mental capacity as required **Consider** Gold Standards Framework / End of Life Care Register when condition changes / deteriorates **Support** completion of ACP if / when admitted to residential or nursing care **Rapid** access to crisis support (essential to know about local services) **Timely** access to information, advice for relatives / carers about common changes; what to do to avoid crisis; who to contact; care and support options **Promote** use of technology to support independence
5	**Nearing the end of life including care in the last days of life**	**Monitor** and review well-being and progression of dementia **Use** clinical prognostic indicators to recognise the dying phase **Review** ACP, agree and communicate management care plan to all involved **Include** on Gold Standards Framework / End of Life Care Register **Consider** palliative care and refer appropriately **Support** relatives understanding & acceptance of the dying phase **Access** appropriate, sufficient support and funding to enable person to be cared for according to their ACP wishes **Recognise** and support person's spiritual and cultural needs

6	**Care after death**	**Provide** advice and support relatives / carers spiritual and cultural needs **Signpost** relatives and carers to appropriate practical bereavement support **Support** practitioners and others to achieve 'closure', reflect and learn