

Norfolk Older People's Strategic Partnership Board

Minutes of the meeting at County Hall, Norwich Wednesday 5 March 2014

Present:	
Joyce Hopwood (Chair)	Norwich Older People's Forum
Ann Baker	South Norfolk Older People's Forum
Lesley Bonshor	Carer's Council for Norfolk
Emma Boore	Borough Council of King's Lynn and West Norfolk
Harold Bodmer	Director of Community Services Norfolk County Council
Denise Denis	Norfolk Independent Care
Hazel Fredericks	West Norfolk Older Person's Forum
Debs Lawrence-Bell	Norfolk County Council Adult Care
Bruce Rumsby	Norwich Clinical Commissioning Group
Paul Jackson	Norfolk County Council Communications
Hilary MacDonald	Age UK Norfolk
Ellis Layward	North Norfolk Clinical Commissioning Group
Rob Jakeman	Integrated Commissioning - West
Ann Clancy	Integrated Commissioning - Norwich
Linda Rogers	Voluntary Norfolk
John White	Norfolk and Suffolk Foundation Trust (mental health)
Emma McKay	NNUH & Acute Hospital Trusts
Emily Millington-Smith	Norfolk Older People's Forum
Kate Money (Vice Chair)	Norwich Older People's Forum
Tony Cooke	South Norfolk District Council
Pat Wilson	Co-opted Member
Jo Ardry	Norfolk Independent Care
Phil Wells	Age UK Norwich
Derek Land	Norfolk Council on Ageing
David Russell	North Norfolk Older People's Forum
Penny Carpenter	Great Yarmouth Older People's Network
Oliver Cruickshank	South Norfolk Clinical Commissioning Group
Niki Park	Norfolk County Council Travel and Transport
Phil Yull	Department for Work and Pensions
Speakers	
Sue Spooner	Consultant, Norfolk & Suffolk Palliative Care Academy
Pam Fenner	Chair, Norfolk and Suffolk Palliative Care Academy and member of the National Council for Palliative Care
Hanne Lene Schierff	Integrated Commissioning Team, West Norfolk
Pauline Elliott	Carer
Elizabeth Hargest	Norwich and Central Norfolk Cruse Bereavement Care
In Support:	
Annie Moseley	Age UK Norfolk
Paul Anthony	Norfolk County Council
Apologies: Sue Whitaker, Niki Park, Jan Holden, Chris Mowle, Anna Morgan, David Button, Jon Clemo, Jane Warnes, Carol Congreve, Nigel Andrews, Shirley Mathews, Catherine Underwood and Carole Williams.	

1	<p>Welcome by the Chair</p> <p>Joyce welcomed everyone to the meeting.</p>
2	<p>Minutes</p> <p>The minutes of the meeting held on 6 November 2013 were agreed.</p>
3	<p>Matters Arising</p> <p>Home Improvement Agency Funding – it was noted that the current County Council contribution to the Home Improvement Agency (HIA) would become part of the Better Care Fund which was the principal agenda item for a future meeting of the Board.</p>
<p>Developing an End of Life Strategy for People with Dementia and their Carers</p>	
4	<p>Introduction by the Chair</p> <p>Joyce explained how the Partnership was helping the Health and Well Being Board with the development of a dementia strategy, and that the last and probably the most difficult element was ‘end of life care’ which was the topic for today’s meeting. She noted that a particularly difficult issue was that the carer of a person at the end of their life might also have dementia.</p>
5	<p>Why Wait – Be Ready For It!</p> <p>- Sue Spooner, Consultant, Norfolk and Suffolk Palliative Care Academy http://bereadyforit.org.uk/</p> <p>Sue introduced the work of the Norfolk and Suffolk Palliative Care Academy highlighting in particular:</p> <ul style="list-style-type: none"> • “Be ready for it” was the slogan adopted by the Academy for their public awareness campaign. • She was helping the Lord-Lieutenant of Norfolk in removing the obstacles to good palliative care in the county. • It is important to start a conversation about the sort of end of life care someone wants before they are unable to make their own decisions. Part of the work of the Norfolk and Suffolk Palliative Care Academy is to train professionals / voluntary sector staff / care homes staff in this approach – how to start and follow through the ‘difficult conversation’. • How people die remains a memory for those who live on - if we can address the difficult questions it helps the bereavement process. • It is easy to make a will, but only 3 in 10 do so. The most difficult issue is talking about death. We need to plan for ourselves – part of the fear is pain / loss of dignity and control / being a burden. • Some 60% of care home staff have no training in palliative care • It is important to complete a Lasting Power of Attorney (LPA). • It is also important to have a conversation about cardiopulmonary resuscitation – ‘do not resuscitate’ requests must be signed and easily accessible. • The Norfolk Clinical Commissioning Groups (CCGs) have recently been working on the development of a ‘Yellow Folder’ which the person

	<p>nearing the end of their life will keep – it is their folder. It will contain key information, including on their support network and their wishes for the care they want at the end of their life (an Advance Care Plan). This information will also be held electronically so that health professionals can access up to date information.</p> <ul style="list-style-type: none"> • Dying Matters Awareness week is 12th – 18th May, and there will be a big event at the Norwich Forum on Wednesday 14th May from 10.0am – 4.0pm, with lots of stalls. In Kings Lynn the Big C will be holding an event on Saturday 18th May which Sue will be attending http://bereadyforit.org.uk/be-ready-for-it-events/ <p>Sue’s presentation was followed by discussions in small groups on key priorities for older people and their carers, to be included in the Norfolk Dementia Strategy.</p>
6	<p>The Journey We Want Pam Fenner, Eastern Region representative for the National Council for Palliative Care, and Chair of the Norfolk and Suffolk Palliative Care Academy, gave a presentation on the journey we want. http://www.ncpc.org.uk/</p> <p>Pam circulated copies of the National Council for Palliative Care publication “Ten Questions to ensure good end of life care in your area” http://www.ncpc.org.uk/sites/default/files/10%20Questions.pdf</p> <p>Pam highlighted the following:</p> <ul style="list-style-type: none"> • In 2009 the National Council on Palliative Care highlighted the message that dementia is everyone’s business, and that this is important across all sectors and professions • People are living longer with multiple conditions that need to be managed, and dementia is often not recognised as being present alongside other conditions • Partnership work is going on in Norfolk to tackle this difficult issue. If the right systems are in place for end of life care, generally they will be right for those with dementia. • By 2020 it is estimated that there will be 15, 730 people with dementia in Norfolk • Locally 44% of people feel that their loved ones are being well cared for, but many do not • A “Gold Standard” model of quality care has been developed to help GPs identify patients near end of life, and co-ordinate services to ensure good planning and delivery of care and support for the person at the end of life and their families. • The National Council for Palliative Care has developed a training resource to help people have the “difficult conversations” and to support the carers • Early conversations are essential and should not be put off • They are working with commissioners and care providers to have proactive systems for co-ordinating care, and are developing an agreed method of sharing information electronically in Norfolk and Suffolk

	<ul style="list-style-type: none"> • A range of services/advice/support should be available 24/7 for people receiving palliative care. Commissioners are working to promote a common understanding about access to a whole range of services • A leaflet on how to work with carers of people approaching the end of life will be available for health professionals. • Commissioners are looking for a common element in contracts so that they can monitor the availability/accessibility of services on the ground for people receiving palliative care and their carers • The Norfolk and Suffolk Palliative Care Academy has a training programme on end of life care, including on end of life care for people with dementia • Some 60% of staff in Norfolk in all sectors have no access to palliative care training, and the Palliative Care Academy is working with commissioners to make this part of their contracts with service providers. • The Academy is working with the Norfolk and Suffolk Dementia Alliance on the core skills needed for palliative /end of life care for people with dementia, and the specialist skills needed including communication skills and pain assessment • End of life care has been identified as a Norfolk priority. A Norfolk and Suffolk Palliative Care summit was held twelve months ago. The Norfolk and Suffolk Palliative Care Academy is playing a key part in helping with the development of a strategic network. • The Clinical Commissioning Groups (CCGs) have communication and engagement strategies to talk to patients and carers and the general public about the services they need, and this will help shape their commissioning activities on end of life care. • Nationally only 2-3% of people receive hospice care – it is very specialised and was built originally on the cancer care model. The skills and expertise of hospice staff should be used in training health and care staff in different settings
7	<p>Example of Good Practice – West Norfolk Hospice at Home Service - Hanne Lene Schierff, Commissioning Manager, Integrated Commissioning Team, West Norfolk .</p> <p>Hanne Lene described the West Norfolk Hospice at Home Service highlighting in particular:</p> <ul style="list-style-type: none"> • That in West Norfolk the majority of palliative care was provided by mainstream generalist service providers. This required good staff training and access to specialist advice. • Support for people who want to die at home including the provision of equipment, clinical intervention and community nursing to help prevent hospital admissions. • Training was necessary, including for GPs who were reluctant to have the ‘difficult conversations’ about the person’s wishes for what they wanted to happen. • They were piloting a Macmillan ‘hospice at home’ with access to high level support for people with cancer – it was being led by national

	<p>research and valuable learning would come from this as most people wanted to die at home but to have the right support and care</p> <ul style="list-style-type: none"> • There were four specialist ‘end of life’ beds available in a local care home with a higher level of clinical intervention • There were special measures in place for people with dementia who might either be the person dying or their carer. • There was a need for consistency of support at end of life – it should be as simple as possible, using the yellow folder and memory aids when necessary, and involving families/carers in decision making. • Medications should be stored properly and there should be good signposting to support services. • It was important to plan for a peaceful ending and make sure the personal wishes of the person dying were written down in advance. • There was a need for access to equipment and assistive technology, and advice on prognosis and symptoms management. • It was important to help people understand legal requirements, and to record wishes for funeral arrangements. • There were a wide range of support services available in preparing for birth and people nearing the end of their life should have the same sort of support. <p>The presentations by Pam and Hanne Lene were followed by discussions in small groups on key priorities relating to “The Journey we want” to be included in the Norfolk Dementia Strategy</p>
<p>8</p>	<p>Loss and Bereavement – A Carer’s Story - Pauline Elliott</p> <p>Pauline described her experiences in caring for her mother, who had dementia, in the period up to and at the end of her life, and the impact this had had on her own life. After a pause, there was universal spontaneous applause for her presentation.</p>
<p>9</p>	<p>Loss and Bereavement – Norwich and Central Norfolk Cruse Bereavement Care - Elizabeth Hargest - Bereavement Support Volunteer and Accredited Trainer Norwich and Central Norfolk Cruse Bereavement Care</p> <p>Elizabeth talked about preparing for bereavement and described the services offered by her service. She highlighted in particular:</p> <ul style="list-style-type: none"> • Older people can find it difficult to adjust to the loss of a significant person in their lives. Death of a child or grandchild can be particularly distressing • There are now many examples of older people caring for very elderly parents. • Grief and mourning is a normal process and with strong feelings including denial, sadness, anger, despair, depression and loneliness which have to be experienced and worked through. • People caring for someone with dementia often feel the loss of the

	<p>person they knew well before that person dies. There may also be added difficulties where family members feel guilt, or have to deal with additional financial or legal problems.</p> <ul style="list-style-type: none"> • It was very important that families were able to be honest and open in expressing their feelings and can talk about pre-bereavement planning, but often there is an inherent reluctance to discuss things. • People with dementia may experience loss as their illness develops, even if they cannot understand why • One to one bereavement support is not necessarily the best sort of help for older people. Alternatives were telephone support or group counselling where individuals support each other. • Cruse support volunteers receive rigorous training and regular supervision and professional development. They also offer bespoke training to other organisations. • Cruse will send an information booklet, but tend to focus on people who need one-to-one support <u>after</u> the normal grieving process. They can help people to find a way to live fulfilling lives after they have had a bereavement. <p>The presentation by Elizabeth was followed by a discussion in small groups on key priorities relating to “Loss and Bereavement” to be included in the Norfolk Dementia Strategy.</p>
<p>10</p>	<p>General Discussion</p> <p>During the general discussion the following points were raised:</p> <ul style="list-style-type: none"> • Being ready – many people do not have relatives or people they trust who can be their Power of Attorney. Would it be possible to set up some form of externalised arrangement? The difficulty of finding someone to take on the role can be a major factor why people do not take out Power of Attorney. • There are big challenges around what as a community we can do to help each other with increasing numbers of older people living alone and/or having no living relatives • There are two forms of Power of Attorney (LPA) – a financial LPA and a welfare LPA. People have the choice to have either or both • The people nominated to have Power of Attorney may no longer be alive or trusted when this needs to be exercised. The process needs to be geared for this • Adults of all ages should be encouraged to make a will, complete an LPA, and prepare an end of life plan. • Carers very often do not recognise themselves as being in a caring role until this is well advanced. Caring for someone to whom you are emotionally attached as an unpaid, informal carer is normally much more difficult than being a professional, paid carer. • Older people often worry about who will pay for their funeral if they have no savings. • People with terminal conditions are sometimes discharged from hospital to a care home, and they then have concerns about meeting the cost. <p>Action: Sue Spooner will include on the ‘Dying Matters’ website advice on</p>

	Continuing Care funding for people needing specialist health care in the last months of their life, as these assessments can be 'fast-tracked'.
11	Informal discussion
	The meeting was followed by Dementia Friends training provided by Laura Meadowcroft, Operations Manager, Norfolk and Suffolk Alzheimers Society.

The next meetings of the Norfolk Older People's Strategic Partnership are on:

**Wednesday 18th June 2014 10.0am – 1.0pm
at Breckland District Council Offices, Dereham**

followed by an informal discussion over a sandwich lunch
with the speakers until 2.0pm.

Members of the public are very welcome to attend.

**Wednesday 24th September 2014 10.0am – 1.0pm
County Hall – Cranworth Room**

followed by an informal discussion over a sandwich lunch
with the speakers until 2.0pm.

Members of the public are very welcome to attend.

**Wednesday 3rd December 2014 10.0am – 3.0pm
at Breckland District Council Offices, Dereham**

Annual Awayday
Board Members only