

Living Well to the End of Life UPDATE

Pan Birmingham 
Palliative Care Network

Issue no 1
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Campaign newsletter for Birmingham, Solihull, Sandwell, Lichfield, Tamworth & Burntwood

“This campaign is essentially about reaching hearts and minds.”

Cynthia Bower, Chief Executive, NHS West Midlands

Launching the *Living Well to the End of Life* campaign on 1st December 2006, West Midlands Strategic Health Authority chief executive Cynthia Bower said it was essentially a ‘hearts and minds’ issue about the quality of care provided to the terminally ill.

“Over the next 18 months we want to get a public debate going in a way that no one has done before on this issue,” she told an audience of nearly three hundred health professionals, voluntary workers, patients and carers at Edgbaston’s Botanical Gardens.

She added: “We’ll be asking what kind of help and support someone needs in their last year or months of life, and we’ll be seeking to involve acute hospitals, hospices, social care, community services and the public.”

Pledging to commit a lot of her own time to the campaign, Ms Bower said the energy and enthusiasm on display at the launch was palpable. “It is heartening to see such a spirit among those who believe we must do something radical about what has tended to be a relatively neglected area of care in the past,” she concluded.



Living Well to the End of Life



We want your support to help change the face of end of life care for everyone diagnosed with a terminal illness.



**Visit our web site at
www.birminghampalliativecare.nhs.uk**



**To join the campaign, please contact
Mel Young or Zoeta Brown on 0121-245 2652
or email melanie.young@westmidlands.nhs.uk
or zoeta.brown@westmidlands.nhs.uk**

**See inside for conference report
and campaign diary**

“We aim to get people talking and thinking.”

**Andrew Donald,
Network Chair**

Pan Birmingham Palliative Care Network chair Andrew Donald said the issues to be addressed by the campaign were those which people tended not to talk about.

But, he argued, a lot of people die what can only be described as 'bad deaths', so radical action is needed to

improve the care and support they receive and to give them real choices.

“We have to raise awareness about these issues, and to get as many people as possible talking and thinking about them. This campaign offers us an opportunity to change the face of end of life care as we know it.”



Above: Andrew Donald holds one of the campaign wristbands that are available from Network hospices for £1 each.



The Living Well to the End of Life campaign is aimed at health and social care, schools, universities, churches, mosques, spiritual centres, businesses and the voluntary and community sectors.

One of the 24 stands in the 'market place' at the campaign launch

“Patients should be offered a gold standard of care.”

National clinical lead for palliative care Dr Keri Thomas told the conference that all patients diagnosed with a terminal illness should be offered a gold standard of care for the rest of their lives.

“It is good when we hear patients talking about having been put on the gold list,” she said. “This new campaign is important because it is about setting the direction of travel for palliative care. It is about enabling patients with a terminal condition to live well before death.”

Stressing that as many as 50 per cent of patients are not dying where they choose, Dr Thomas said that doing nothing was not an option. With better

planning and more attention given to crisis prevention, more patients could be expected to die where they choose. A greater focus on community care would also help to reduce hospital admissions and costs.

“About one per cent of the population die each year,” she said. “Every GP has about 20 patients who are in the last year of life. The question that needs to be asked in each case is: how can we make the best of that last year?”

She concluded: “The baby boom generation is now reaching old age. If it can succeed in transforming the way that we approach death and dying, that will be a tremendous legacy to leave to the next generation.”



**Dr Keri Thomas,
National Clinical Lead
for Palliative Care**

The campaign aims to ensure that any patient, from diagnosis to the advanced, non-curative stage of disease, lives well and dies well in the place and in the manner of their choosing.



A chance to network during a break at the launch event



**Rev Dr Barry Clark,
Chaplain, University
Hospital Birmingham**

“Don’t leave things to chance.”

The importance of involving patients in making the choices that are best for them and their families was stressed by Rev Dr Barry Clark, chaplain at University Hospital Birmingham.

Dr Clark described how people with terminal conditions had helped to create *When the Going Gets Tough*, a guide to how decisions should best be made at key stages in the progress of their illness towards death. “It’s a way of making sure that things are not left to chance,”

he said. “It has been designed as a screening tool to be used at the appropriate time.”

Dr Clark also made a plea to health care professionals in hospitals to make use of their chaplains in ensuring that patients’ spiritual needs were met. “We live in a secular society and death can be very clinical. But we do need to take account of the spiritual dimension in people’s lives.” **To find out more about the screening tool, email barry.clark@uhb.nhs.uk**

“What would you want for yourself and your family?”

Helen Meehan, Lead Nurse for Palliative Care, Solihull Care Trust

Solihull-based palliative care lead nurse Helen Meehan said that if she or a member of her family were diagnosed with a terminal condition, she would want them to receive reliable, high quality services that met their specific needs and enabled them to exercise real choices about what happened to them.

Describing how palliative care services

in Solihull had been moving in the right direction over the past two or three years, she said that from November 2006 all general medical practices in the borough had signed up to deliver care in accordance with national ‘gold standard’ principles.

“There is also now a 24-hour district nursing service available to patients with a terminal condition,” she said.



“We need better co-ordination.”

Dr James Beattie, National Clinical Lead for Heart Failure

A reminder that the importance of good palliative care goes well beyond the needs of cancer patients was provided to the conference by Dr James Beattie, national clinical lead for heart failure.

Overall, heart failure has a 50 per cent mortality rate within four years of diagnosis. For patients with the severest forms of heart failure, the mortality rate is 50 per cent after just one year.

This, Dr Beattie stressed, means that heart failure can potentially be as

serious as cancer for many patients, but with a more unpredictable end phase which may see them in and out of hospital as the condition progresses.

“We need to co-ordinate end of life care better for heart failure patients and those affected by other forms of organ failure,” he said. “A framework for that care might include symptom control, rehabilitation, psychological support, social support and spiritual support, as well as general and specialist palliative care.”



**Peter Holliday,
Chief Executive,
St Giles Hospice**

“No one should fall through the gaps.”

Peter Holliday, chief executive of St Giles Hospice near Lichfield, emphasised the critical importance of having a network of services which ensured that patients with a terminal condition did not fall through any gaps.

“Hospices have their roots in the local community,” he said. “One of the major challenges of this new campaign will be to see how far the principles of palliative care that are practised in the hospice setting can be extended elsewhere.”

Describing the work of St Giles Hospice, Mr Holliday said its 200 staff and 900 volunteers provided care and support to some 350 patients every

week of the year. He added: “As well as receiving about a third of its £5.4 million annual funding from the NHS, the hospice relies on local fundraising work, sales of products in its charity shops and the proceeds of its own, highly successful lottery that is regularly played by around 30,000 people.”

Mr Holliday said that with more people predicted to live into their late 80s and beyond, health and social care services would need to provide the right support to those affected by terminal conditions, some of which might entail months of gradual deterioration prior to death.

“By befriending death, we can live well during life.”

Reverend Dr James Woodward, vicar of St Mary's Church and master of the Leveson Foundation at Temple Balsall, near Solihull, said it was vital that professionals listened to what the dying had to say about the support they needed and where they would prefer to spend their last weeks and days.

“The virtues we need to see reflected in the way that health services treat people who are terminally ill include respect, truth and compassion,” he said.

“We do not have to let people die on the busy wards of acute hospitals. We

do not have to let bad news be broken badly to them and their families. We have to discuss how, by befriending death, we can live well during life.”

Referring to the reasons for launching *Living Well to the End of Life*, Dr Woodward concluded: “It is not surprising that we need the campaign. Very few people under 40 years old have been to a graveside burial. Very few have been close to a dead body. We live in a world that sees death and dying as alien territory. Yet these are issues that need to be faced with imagination and humanity.”



**Rev Dr James Woodward,
Vicar of St Mary's Church,
Temple Balsall, and
Master of the Leveson
Foundation**

“Co-ordinator, navigator, companion”

Manjula Patel, manager of the Sandwell-based Bridges organisation that provides support to people with a terminal illness, said many people did not realise what help was available to them.

“Bridges ensures that patients receive whatever support they need,” she said, “whether that is someone to do the housework, transport them to hospital for treatment or simply talk to them when they are down.”

Describing how one patient who had contacted Bridges nearly turned down radiotherapy

treatment for his cancer because he did not think he would be able to make the journey every day, Manjula said that help had been only a phone call away. “We were able to ensure that he received the treatment he needed at that point in his illness,” she added.

Bridges uses stories of patients' lives and experiences to help illustrate the importance of addressing individuals' needs.

“Listening to people's personal stories is empowering,” she said. “It enables them to identify their own needs and helps to promote

their own self-esteem. As far as Bridges is concerned, we try to fulfil a supporting role, sometimes as a co-ordinator of the support they need, sometimes as a navigator to help them identify what would be best for them, and sometimes as a companion.” **To find out more about Bridges, email manjula@murrayhall.demon.co.uk**



**Manjula Patel,
Manager,
Bridges Project**



**Tina Fisher,
Chief Executive,
St Mary's Hospice**

“Not somewhere to die, rather a place to live well before death”

St Mary's Hospice chief executive Tina Fisher explained that good palliative care was about improving a dying person's quality of life while they were still living.

“Many people may think that hospices are places where people go to die,” said Tina. “But patients who experience hospice care change their perspective and see palliative care as something that helps them to live well in the period before their death.”

She added: “It may mean that their symptoms are better controlled, and it

may mean that they are able to enjoy simple things such as getting out in the garden and enjoying the fresh air.”

Tina described the case of John, who had experienced successive amputations over three years because of his deteriorating condition. “During that period he had either been knocked out on morphine or in severe pain,” she said. “Within 24 hours of being admitted to the hospice, he felt a lot better, telling us that we had literally given him his life back.”

“Planning for death is as important as planning for birth.”

Consultant geriatrician Dr Jonathan Trembl from Selly Oak Hospital said good planning from the earliest possible stage was essential to ensure that patients diagnosed with both malignant and non-malignant terminal conditions received the right kind of care and support.

“Most mothers-to-be have a birth plan in place,” he said. “But we don't yet do that routinely for people who are approaching death. Waiting until someone is very close to death is too late to give them the choices they have a right to make.”

He added: “To provide the best possible quality of palliative care, you need to anticipate the terminal phase of

an illness and to start planning a care pathway from the moment of the initial diagnosis. Different diseases, depending on whether they are of a malignant or non-malignant variety, take different courses.”

Describing the principles behind a tool known as the *Supportive Care Pathway*, Dr Trembl said it aimed to ensure good practice in end of life care, and to empower patients, carers and staff.

The tool has been developed to improve links and communication between different services and teams. A daily sheet that is quick and easy to complete is used by all team members to record significant factors about the patient's condition and needs.



**Dr Jonathan Trembl,
Consultant Geriatrician,
Selly Oak Hospital**

For further information on the pathway, email jonathan.trembl@uhb.nhs.uk or jill.main@sbpct.nhs.uk

“Many health professionals do not have the training to break bad news.”

Figures presented at the launch event by Sandwell Primary Care Trust public health consultant Dr Kshesh Sidhu showed that only a minority of people with incurable cancer, heart failure, kidney disease and dementia currently die at home, despite surveys which have found that the vast majority would prefer to end their days in familiar surroundings rather than in the more clinical environment of a hospital.

“Many health professionals do not have the training and confidence to break bad news to patients who are very sick and at their most

vulnerable,” said Dr Sidhu. “Unfortunately, a lack of preparedness for dealing with this sort of situation means that there is often uninformed decision making about what should happen, and many people die without their wishes being heard.”

Reviewing the changes in the principal causes of death over the past fifty years, Dr Sidhu said that deaths had been increasingly accounted for by the chronic diseases of old age rather than infectious diseases.

Looking to the future, he signalled an anticipated 200 per cent rise in

the number of over-85 year olds in the West Midlands by 2030.

This would be happening, he said, at a time when the pool of younger people who would otherwise be pursuing careers in health and social care organisations, or offering themselves as volunteers to help out, would not be expanding.



**Dr Kshesh Sidhu,
Consultant in
Public Health
Medicine, Sandwell**

“We are launching CWASIs and a Dialogues in Dying DVD.”

Pauline Smith, End of Life Care Lead, NHS West Midlands

A number of new initiatives to help health professionals and others engaged in palliative care delivery were highlighted by Pauline Smith, end of life care lead at NHS West Midlands.

First, Pauline introduced the audience to the concept of the CWASI, or ‘consultants with another specialist interest’. They were, she explained, consultants who wanted to develop an enhanced level of palliative care practice.

Each new CWASI would be expected to provide clinical leadership in the development of palliative care services within their own organisation.

She said: “Three acute hospital trusts are involved so far in the pilot phase - Heart of England, University Hospital Birmingham, and Sandwell and West Birmingham Hospitals. The first

cohort of CWASIs are expected to commence in March 2007.”

To find out more about CWASIs, email diane.webb@st-giles-hospice.org.uk

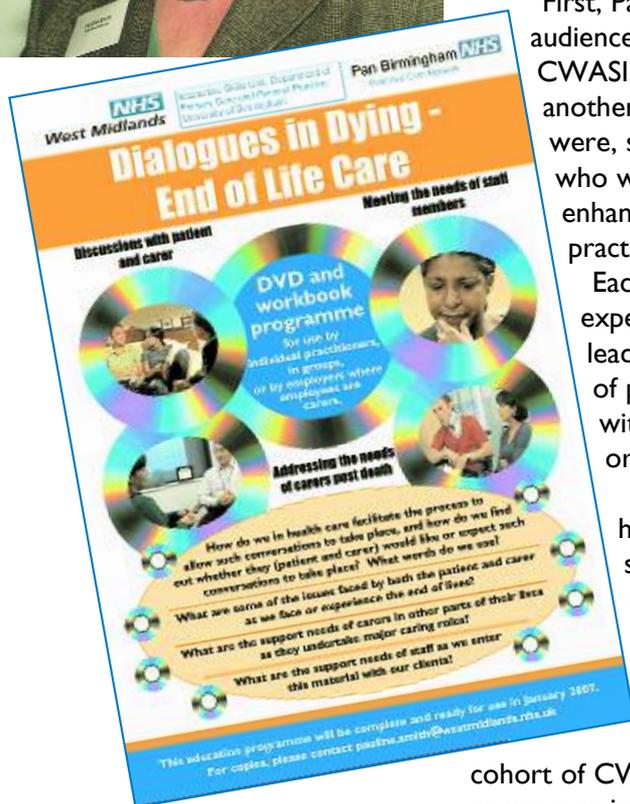
The second initiative flagged up by Pauline is called *Dialogues in Dying - End of Life Care*. It consists of a DVD and workbook for use by individual practitioners, groups of clinicians or employers whose employees are carers.

To be launched in January 2007, the programme aims to help boost awareness of the issues around death and dying.

“We all need to become more attuned to talking about them,” said Pauline, who explained that she and colleagues were also exploring a number of other ideas, including the use of individuals’ personal stories to help the public and professionals to understand the key issues.

She added: “We are also looking at how enabling terminally ill patients to listen to their favourite music or poetry might contribute to the overall palliative care support they receive.”

For copies of the DVD and workbook, email pauline.smith@westmidlands.nhs.uk



Living Well to the End of Life

Campaign diary for 2007/08

Our campaign will run to June 2008. The focus will be on people power, raising their awareness about the services available and those which need to be available. Each month will have a specific focus, with two simple actions that each organisation participating in the campaign can complete, plus one **BIG ACTION**. Alongside these activities, we will be running a series of Celebrate events involving all the creative arts and all the diverse communities within the Network's area. See below and on page 8 for further details.

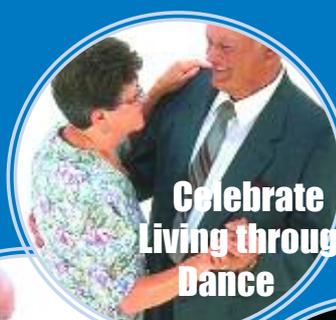
December 2006	Launch: Starting the conversation - getting everyone to think about it
January 2007	How are we communicating with people at the most vulnerable times in their life?
February 2007	Communicating across organisations - 'Hi, how are you? Can we talk about...'
March 2007	Advanced care planning - 'We need to start talking about this when we are well.'
April 2007	How do we know we are getting this right?
May 2007	Getting out of the closet! Tell everyone about what you do - get out there!
June 2007	Everybody happy and part of a team? Let's look after each other too.
July 2007	Fundraising!
August 2007	Tell us your story
September 2007	Hospital care - let's get to be the best in the world for these patients.
October 2007	Hospice care - spreading the word
November 2007	Primary care teams and out of hours - let's deliver a world class service.
December 2007	Care homes - we can really get this right.
January 2008	Children and young people's services - this has got to be right!
February 2008	Social care - we are committed to this!
March 2008	Volunteer services and Bridges - let's get this really started.
April 2008	Innovations! Build!
May 2008	My business supports its employees.
June 2008	Let's celebrate, now we can say our name - The roll call!

Celebrate - other activities planned

**Celebrate Living
Summer Ball:
July 2007**



**Celebrate Living
Christmas Concert:
December 2007**



**Celebrate
Living through
Dance**



**Celebrate Living
Photographic
Exhibition**



**Celebrate Living
through Faith**



**Celebrate Living
by Story Telling**



**Celebrate
Living Arts**

Living Well to the End of Life

First steps to take in January 2007

Two simple actions: smiling and interacting

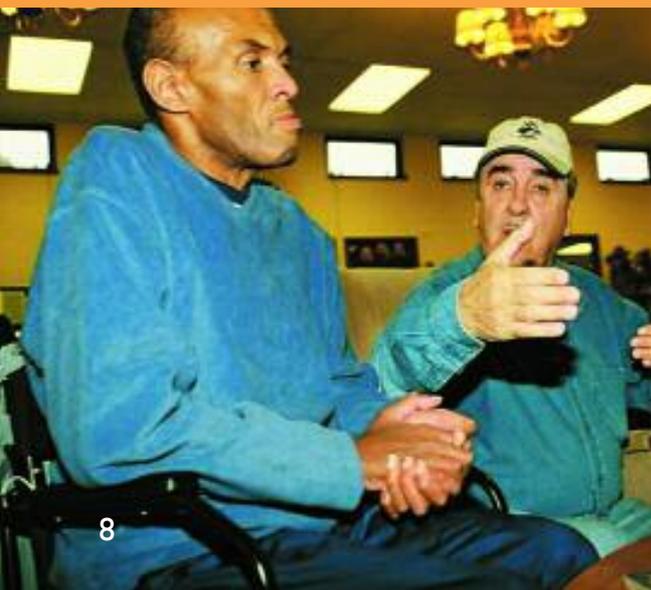


Smile, and smile back. It takes half as many muscles to smile as it does to frown, and it makes you and others feel twice as good.

Spend time with someone from a different generation. Both of you will benefit - try it and see.



Plus one BIG ACTION:



Learn how to listen. Then learn how to communicate.

Email the team - we have all the resources to help you.

**melanie.young@westmidlands.nhs.uk
zoeta.brown@westmidlands.nhs.uk**

When you have completed your actions for each month, tell us your story!