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TABOO-BUSTING END OF LIFE PROJECT SET TO LAUNCH

A new book based on the real experiences of patients and carers is being launched this week to tackle the myths about death and dying.

The nationally acclaimed storyteller, Maria Whatton, has spent the last twelve months working alongside NHS West Midlands and Bridges Support Service to help a group of people from Sandwell and parts of Birmingham develop a new public resource of stories about and for the end of life. The First Primrose is being launched at an event on Thursday 17 July.

The book reflects the announcement made this week by the government to encourage the public to talk about the issues of death and dying and give people more choice on where they would like to die. The national End of Life Care strategy launched this week committed £286m to provide high quality care for all adults approaching the end of their life.

Based on the real experiences of participants, the stories are also available to the general public through a new website: www.wellbeingindying.org.uk. Visitors to the website will not only be able to read the stories, but also listen to them as well as watch short films and explore the participants' collections of photographs.

Inspired by these everyday stories, Maria Whatton has created her own modern folk tale, 'The First Primrose', which tells the story of Mischa and Stephan. We follow their heartbreaking journey through the Forest of Fear, the Valley of Hope and the Lake of Tears until the bittersweet wisdom of the first primrose is finally and unforgettably revealed. This story will be premiered on the website and available as a downloadable audio book read by Maria.

"We hope the stories on this website offer everyone a way of becoming more familiar with death and dying. By telling these stories the people involved are putting something in place for future generations", says Pauline Smith End of Life Care Lead at NHS West Midlands. There are witnesses to death as well as those who have had a taste of their own mortality".

Manjula Patel Bridges Support Service Manager, who was heavily involved in the recruitment of and working with the participants alongside Maria to capture their stories is keen to reinforce the value of this piece of work. She says: "It has been so important

to provide the opportunity to these very willing community members to regenerate the use of stories to help and make real how we live with dying”.

“We all need to be part of how we die well, but we seem to have become disconnected and forgotten how to accept that death and dying is a natural part of life. As the stories clearly illustrate there is no such thing as one formula for death”.

Stories are mediums that help individuals to make sense of their experiences. Stories are powerful and it’s through stories that individuals and communities construct understanding of what has happened or is happening to them. It is only by listening to those who have experienced this journey that others can understand and be better informed.

Malcolm Bailey, Chief Executive of Murray Hall Community Trust, says: “Maria has created a contemporary folk tale type myth about life, dying and death. She has done this beautifully by drawing together key elements from a number of real life stories which tell us about aspects of living, dying and death. These real life stories were collected from some of our local residents in Sandwell and Birmingham. We have here a project that gives us that everyday perspective on dying and death and is much to be commended for the simplicity of doing this.”

-ENDS-

For more information contact:

NHS Communications team at NHS West Midlands, Tel: 0121 695 2252 or Sandwell PCT Tel: 0121 613 1535. Interviews are available with author, Maria Whatton and some of the people who have contributed to the book.

Editor’s note

The First Primrose is being launched on Thursday 17 July, 5.30-7pm at the Public, West Bromwich.

NHS West Midlands is the Strategic Health Authority for the West Midlands. The NHS in the West Midlands is made up of 43 NHS organisations spending £8 billion on health services for 5.4m people. As the local headquarters for the West Midlands, it sets the overall direction for the health service in the region and puts the systems and programmes in place to deliver the service.

Bridges Support Service is a supportive care service supporting people living with cancer and palliative care needs in Sandwell and parts of Birmingham. The service is a bridge to access services from health, social and community organisations and where there are gaps Bridges provides appropriate support. Bridges is managed by Murray Hall Community Trust a registered charity.

The development of the Bridges service has intrinsically been linked to patients and carers stories. Bridges has also pioneered the ‘Narrative Based Assessments’ to enable the service to provide tailored support based on the patient’s story.