Dying Matters

Awareness Week
2-6 May 2022

How you and your library can get involved

hospiceuk.org/dyingmatters
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Introduction

Libraries are at the centre of thousands of communities across the UK, providing an ever growing range of services to the public. Building on the work of death positive libraries, and in the context of the COVID-19 pandemic, we know that many library staff are often asked to support and advise library users with planning for death and with grief.

Dying Matters Awareness Week exists to help create a space for communities to have conversations about death and dying in whatever way works for them. We understand it’s a topic that makes people feel anxious; it can feel hard to talk about, and people often worry about saying the wrong thing. What we want you to know is that very often, simply listening, and perhaps knowing a few services to signpost to, is all that’s needed.

This year, we’re campaigning for everyone to be #InAGoodPlace when they die; that might mean physically, emotionally, financially, spiritually, and with the right care in place. This pack is full of ideas and resources to help you and your library encourage your community to be #InAGoodPlace at the end of life.

A welcome note from Libraries Connected

We are delighted to work with Hospice UK to support the development of this resource to help libraries engage with Dying Matters Awareness Week. Libraries are uniquely placed as a centre for conversation, providing inclusive community-based activity and support, and a trusted space where issues around death and dying can be explored with caring staff on hand to help.

The event ideas and suggestions in this pack for libraries offer some brilliant opportunities to raise awareness of the Dying Matters campaign, and ways to support and advise their communities. Libraries Connected is continuing to develop work on death positive libraries, as part of our Universal Health and Wellbeing Library Offer. Working with partners, such as Dying Matters, helps us to create new ways to build on this offer for library services. We hope this will give you the inspiration to get involved!

Share your events and activities online and via social media. Don’t forget to register your event on the Dying Matters website, and tag Libraries Connected on Twitter @libsconnected, and Dying Matters @dyingmatters too.

Isobel Hunter, Chief Executive, Libraries Connected

hospiceuk.org/dyingmatters
Five books to help us think about dying and grief, by Kathryn Mannix

Kathryn Mannix is a former palliative care doctor, author of ‘With the End in Mind’ and ‘Listen’, and campaigner for better understanding and less fear of dying. ‘With the End in Mind’ is her account of how people live the last part of their lives, aiming to demystify dying and help us all to recognise and be consoled by understanding the process of ‘ordinary dying.’ It is a beautiful, uplifting read.

Books take us to new places in our minds, open us up to new ideas and expand our imagination, knowledge and worldview. The most challenging of human experiences have always featured in storytelling. Death, dying and grief occur repeatedly in fiction, allowing us to explore them through the mind’s eye of characters; non-fiction offers us a variety of insights into living and dying, grief and mourning, written by individuals describing their own experiences and by experts offering a summary of current wisdom.

So where shall we start? Death is included in children’s literature, and it is important that it is. Experiencing the death of characters in a book is an introduction to the fact of mortality: Beth March in Little Women, Matthew Cuthbert in Anne of Green Gables, Mog the beloved protagonist of the Mog series of picture books, Badger in Badger’s Parting Gifts.

In adult non-fiction, pathobiographies give us a glimpse into the world of people who know themselves to be terminally ill. Before I Say Goodbye (Ruth Picardie), PWA (Oscar Moor), C: Because Cowards Get Cancer Too (John Diamond) were written by journalists, and their fine writing popularised the genre.

Later thought-provoking works include When Breath Becomes Air (Paul Kalanithi), The Unwinding of the Miracle (Julie Yip-Williams) and, my personal favourite for the beauty of his writing, Joe Hammond’s A Short History of Falling, in which he describes the onset and progression of his motor neurone disease alongside his love and fascination for his family and for nature.

Whilst autobiography describes a single person’s view and experience, books by ‘expert witnesses’ offer us a different insight as they lay out the territory from the common to the rare, offering the reader a guided tour of their subject. One of the earliest of these, and still both relevant and compelling, Sherwin B Nuland’s How We Die offers a medical interpretation of the mechanisms that bring about dying from a variety of causes. Both factual and fascinating, it confines itself to information with little emotional exploration. In contrast, The Way We Die Now is physician Seamus O’Mahoney’s heartfelt cry for a new attitude to end of life care in hospitals, where he sees death ignored and futile treatments prioritised.

Please see the resources section for further book and reading list suggestions.
How you can get involved

On Dying Matters Awareness Week, we’re asking you to:

Host your own event

It is more important than ever for us to come together and talk about death, dying and grief. You can host your own virtual or in-person event, or search for what’s going on in your area.

Planning an event? Make sure you register your event now. →

Want to get involved? See what’s on during the week →

Spread the word

There is no right or wrong way to grieve, and everyone experiences it differently. Sharing stories can help create spaces for people to talk openly, share experiences and support each other.

We’ll be sharing stories online:

Our website → Facebook → Twitter → Instagram →

Join the movement

We can’t do any of this alone. We need your to raise your voices and join the movement to make sure that people of all ages are in a good place when they die.

Add your name today →

Write to your MP

We know that not everyone gets the quality end of life care they deserve. Help us show our political leaders what is needed to make end of life care accessible to everyone across the UK, no matter who they are.

Take action with us today and write to your MP →

Let’s get MPs talking about death and dying too – and taking action – so that everyone can die #InAGoodPlace.
Event ideas and suggestions

“We ran a Dying Matters Week coffee and chat, in partnership with Kirkwood Hospice. We created a space in the centre of the library for tea, coffee and time to talk, with information about local bereavement support. We also had a book display including fiction that featured the death of a character, non-fiction around bereavement and self-care, poetry and mindfulness books and picture books to help families talk about death with children.

We had a couple of notice boards where people could share the things on their bucket list and share words they would use to describe someone who meant a lot to them who had died. A lot of people just wanted to talk and share their memories and thoughts, some wanted to sit and browse the books, others wanted to take part and contribute to the boards.”

Kirklees Library, West Yorkshire

“Aura Libraries are new to Dying Matters and we are looking forward to participating in Dying Matters Awareness Week 2022. As this will be Aura Libraries first year as an introduction we will be holding coffee and chat sessions in libraries for customers, this will allow them to share memories of their loved ones, have conversations and express their experiences.”

Rheolwr Gwasanaeth Llyfrgell, Library Service Manager, Hamdden a llyfrgelloedd, Aura Leisure & Libraries, Wales

“In partnership with a local solicitors’ firm, Oldham libraries were delighted to bring to their central flagship venue a whole host of partners and activities to raise awareness of Dying Matters with a special festival event. The event included information stalls and activities delivered by a variety of partners including representatives from charity sector, health sector, inter-faith groups, funeral homes and legal services.

We also hosted a ‘lightning talks’ series on a range of topics, such as death myth-busting and will writing, and all participants received an event passport that invited them to record preparation plans for later life and end of life. Pinning the event on the national campaign resources supplied by Hospice UK not only provided messaging and branding to unite partners under, but also provided sector awareness that brought partners directly to us. Splitting the workload with Harold Stock and Co. Solicitors massively increased both our capacity and network, enabling the realisation of a significant hub of activity on a shoestring budget.”

Oldham Libraries, Greater Manchester
How to promote Dying Matters Awareness Week

Spread the word via your website and social media, and in and around the library, encouraging your community to engage with the campaign and talk openly about death, dying and grief.

Key messages: long version

Dying Matters Awareness Week, 2-6 May, is our chance to get talking about death, dying and grief.

We want everyone to be #InAGoodPlace when they die – crucially, with the right care and support in place.

Right now, we know that people are dying without the support they need. Since the start of the pandemic, it is estimated that almost 70,000 people have died at home without access to specialist care. The past two years have accelerated this issue like never before.

We know that it’s by talking, and by sharing stories, that we can change the conversation about death. When we talk about dying and grief, we remove the taboo and stigma that have for too long surrounded these topics. And we can also better understand what’s happening in our communities so that political and healthcare leaders know what is needed to make end of life care accessible to everyone in the UK.

Dying Matters Awareness Week, 2-6 May, is our chance to join the Dying Matters movement – to get talking about death and dying, and to call for end of life care for all. 

Let’s talk about death and dying, so that everyone can die #InAGoodPlace, no matter who they are.

Key messages: short version

Dying Matters Awareness Week, 2-6 May, is our chance to get talking about death, dying and grief.

We want everyone to be #InAGoodPlace when they die – whatever that means for them.

Right now, we know that people are dying without the support they need. And we know that it’s by talking, and by sharing stories, that we can remove the taboo and stigma that surround these topics.

Dying Matters Awareness Week is our chance to get talking, to share stories, and to call for end of life care for all. Join the Dying Matters movement today.

Your call to action

Let’s talk about death and dying, so that everyone can die #InAGoodPlace, no matter who they are. Join the Dying Matters movement today.

hospiceuk.org/dyingmatters
Materials

These resources will help you talk about Dying Matters Awareness Week on your channels. All resources can be downloaded here.

You will also find them on the Dying Matters website →

Social media graphics ➔

Social media images ➔

Social headers ➔

Dying Matters logos ➔

Template press release ➔

Don’t forget to tag @DyingMatters and use the hashtags #InAGoodPlace or #DMAW22

hospiceuk.org/dyingmatters
Resources

Downloadable leaflets

We have 5 downloadable leaflets including:

**Things to do before you die:**
How to get started with thinking about what you want at the end of life, and starting to plan.

**Supporting bereavement:**
It can be hard to know what to say or do when supporting someone who is bereaved. This leaflet is full of useful tips on how to help yourself and others in this difficult situation.

**Let’s talk about dying:**
Talking about dying doesn’t make it happen, but it still feels taboo. This leaflet will help break those barriers and get you talking about the inevitable.

**Talking about dying with people affected by dementia:**
Talking about dying isn’t always easy, but it can be more difficult if you are supporting someone with dementia. This leaflet is designed to support you through those conversations and get you talking and planning earlier with the ones you love.

**Talking about dying with children:**
We can’t protect children from death. This leaflet will help you talk to children to alleviate any fears or misunderstandings they may have about death and dying.

What to expect when someone important to you is dying:
If you are caring for someone who is in the last stages of life, or who may be soon, this information is for you. It is designed to help prepare you for what to expect in the very last days and hours of a person’s life. Read more →
Resources

Resources on death and dying for libraries

Libraries Connected – Death Positive Libraries Find out more about the work libraries are doing to support communities in talking about death, dying and bereavement. librariesconnected.org.uk/news/death-positive-libraries-national-framework visionrcl.org.uk/libraries-heritage-culture/health-and-wellbeing/the-death-positive-library/

The Death Positive Libraries Book List This book list was created as part of the Death Positive Library Project by Redbridge, Kirklees and Newcastle Libraries and Northumbria University, with recommendation and contributions from the libraries project team, expert researchers at Northumbria University, various project partners, reading group authors, attendees at events and selected from relevant websites. https://www.librariesconnected.org.uk/page/death-positive-libraries-book-list

Healthy Living Through the Health and Wellbeing Offer, libraries promote healthy living, provide self-management support and engagement opportunities for children and adults supported by welcoming spaces, effective signposting and information to reduce health, social and economic inequalities.

Find out more about this work including Reading Well, a shared programme between Libraries Connected and The Reading Agency which seeks to support health and wellbeing through bespoke book lists. Reading Well have also worked with Cruse Bereavement Care to recommend helpful resources that can help libraries find information on supportive services, advice on coping with grief, and suggestions for what to say to a bereaved person. https://www.librariesconnected.org.uk/universal-offers/health-wellbeing https://reading-well.org.uk/news/bereavement-support-and-death-positive-libraries

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Support and advice

**Ataloss** Help for people who have been bereaved. Includes a search tool for local support, griefchat service, Grablife activity support weekends, bereavement support for men, and support for young people.
[ataloss.org](https://ataloss.org)

**Child Bereavement UK** provides information and support (including a helpline) when a baby or child of any age dies or is dying, and when a child is facing bereavement.
[childbereavementuk.org](https://childbereavementuk.org)

**Compassionate Employers** is Hospice UK’s workplace support programme, helping organisations and their employees to build an open, compassionate culture to support staff through grief, caring responsibilities, or a life-limiting illness.
[www.hospiceuk.org/compassionate-employers](https://www.hospiceuk.org/compassionate-employers)

**Cruse Bereavement Care** is a national charity, which provides support, advice and information to children, young people and adults when someone dies.
[cruse.org.uk](https://cruse.org.uk)

**The Good Grief Festival** is a brilliant community of people talking about grief in a refreshing and honest way, with virtual talks, workshops and webinars held at online festivals through the year.
[goodgrieffest.com](https://goodgrieffest.com)

**Hospice UK’s planning ahead tool**, developed with palliative care expert Kathryn Mannix and others, leads you, step by step, to think about your own values and the things that matter most to you in life and in dying. It will explain some of the treatment decisions that may lie ahead and ask you to think about whether the length of your life, or the quality of the way you live, matters more to you:

**Hospice UK’s guide to end of life care** provides clear and concise guidance about what to expect, what to ask and where you can get support when you or a loved one are facing the end of life.

**Marie Curie** The Marie Curie Support Line provides practical and emotional support for anyone who’s been bereaved, whether it happened recently or some time ago. You can also get ongoing support from a bereavement volunteer.
Support Line: **0800 090 2309**
Online information and support: [mariecurie.org.uk/support](https://mariecurie.org.uk/support)
Booklets and resources, including easy read versions: [mariecurie.org.uk/publications](https://mariecurie.org.uk/publications)

[hospiceuk.org/dyingmatters](https://hospiceuk.org/dyingmatters)
Support and advice (continued)

Sands is the leading stillbirth and neonatal death charity in the UK. Sands exists to reduce the number of babies dying and to ensure that anyone affected by the death of a baby receives the best possible care and support for as long as they need it. sands.org.uk

Sue Ryder supports people who are living with a terminal illness, a neurological condition or who have lost someone. sueryder.org

WAY (Widowed & Young) Foundation WAY is the only national charity in the UK for men and women aged 50 or under when their partner died. It’s a peer-to-peer support group run by a network of volunteers who have been bereaved at a young age. It runs activities and support groups for people coping with grief. widowedandyoung.org.uk

Winston’s Wish. A child bereavement charity which offers specialist practical support and guidance to bereaved children, their families and professionals. 08088 020 021 winstonswish.org.uk
Dying Matters is led by Hospice UK.


For more information visit: hospiceuk.org/dyingmatters