

The session will begin shortly



Improving End of Life Care for People with Learning Disabilities & Autistic People



COMFORT BREAKS



BEHAVIOUR



TECHNOLOGY



TIME KEEPING

Housekeeping (Virtual)



CONFIDENTIALITY



STRUCTURE



ASK QUESTIONS



KEEP LEARNING

Improving End of Life Care for People with Learning Disabilities & Autistic People

Louise Jenkins

Strategic Lead Nurse for the
Community Learning Disability Nursing Service



What do we mean by end of life ?

End-of-life care in the UK refers to the **comprehensive support and medical treatment** provided to individuals who are nearing the end of their lives, often due to terminal illness or advanced age. It encompasses the **physical, emotional, and social needs** of a person, aiming to help them live as well as possible in their remaining time and to die with dignity [___khh.org.uk+2](http://khh.org.uk+2). This care is typically provided in the last months or years of life and includes support for both the individual and their families [___www.nhs.uk](http://www.nhs.uk).



How do we know if someone is end of life ?

Some people's death is expected as the person has been diagnosed with a terminal health condition, and although they may still be offered treatment to reduce the symptoms and pain, the condition cannot be cured.

Other people's deaths may come as a shock, as they may have health conditions and times when they became unwell but always recovered. But...were the signs there?



How do we know if someone could be in their last year of life ?

- General physical decline, increasing dependence and need for support
- Repeated unplanned hospital admissions or acute crises at home
- Advanced disease - unstable, deteriorating, increasing complex symptoms
- Presence of several health conditions and health risks
- Decreasing activity –limited self-care, in bed or chair 50% of day and increased dependence on others for activities of daily living
- Decreasing response to treatments, decreasing reversibility
- Patient choice for no further active treatment, focus on quality of life
- Progressive weight loss (more than 10%) in past six months
- Significant event e.g., serious fall, bereavement, moved to a new home



How do we know if someone could be in their last year of life ?

**We also use something called the “surprise question” which is
“Would you be surprised if this person died in the next 12 months?”**

If your answer is no, then there is a reason why you are instinctively feeling this, and there are probably clues that you’ve picked up while caring for this person.

Supporting the people you care for to have a good death is something you can’t do on your own. We have developed pages on the HCPA Directory that will guide you on what is expected by CQC and HCC and how you can deliver this.



Why have we developed these Guidance pages?

There are several reasons;

- So, that people with learning disabilities get the best care possible at the end of their life
- So, you are clear, as care providers, what is expected of you and your team
- So, that your team feel supported by the appropriate specialists that value the skills and knowledge of your support staff
- So, that support staff do not feel traumatised, anxious or frightened by being asked to support someone who is dying



HCPA Directory End of Life pages

The end-of-life page is here on the HCPA Directory **EOL care for LD and Autism – HCPA**

The page is divided into sections so you can find information easily.



- Introduction
- Planning Ahead
- Support - Who can help with end-of-life care?
- My Plans and Communications
- Recognising Symptoms and Management
- Within the last year of life
- Actively dying
- Who can help?
- After Death
- Appendices

HCPA Directory End of Life pages

The sections are split up to help guide you to;

- Find out what the end-of-life wishes are for the people you support
- Understand what services can support with this
- Recognise those people who may be in their last year of life
- Provide excellent end of life care when needed



Introduction

Planning Ahead

Support - Who can help with end-of-life care?

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Actively dying

Who can help?

After Death

Appendices

How do I know where to start?

We have created a Checklist for paid carers that will guide you with where to start;

[Appendix-2---Checklist-for-paid-carers-to-facilitate-a-good-death.pdf](#)

This will give you a sense of what you already have in place or what you need to get started on. We are already seeing some great examples of excellent end of life care through LeDeR Reviews, so we know it can be done.



Appendices – examples of resources

The appendices has resources for carers and people with learning disabilities to help have some conversations about people wishes when they die. Here are some of the examples;

Kingston University has produced an End-of-Life Toolkit to help people with learning disabilities

[Victoria and Stuart Project](#)

Palliative Care for people with Learning Disabilities Network - [PCPLD](#)

Marie Curie have developed resources that are helpful - [Marie Curie Resources](#)



Now its up to us all to work together!

This is only the beginning....we will continue to add examples and new resources to the pages so that this remains up to date and relevant to you all.

Please encourage all staff to read the information on the page or look at it together in a team meeting.

If you have any ideas about how to improve the web pages, please let me know. It's important that these are helpful and give you the information you need to give excellent end of life quality care.

My Email is louise.jenkins@hertfordshire.gov.uk



Any questions or comments?





New Resource

Introduction

Planning Ahead

Support - Who can help with end-of-life care?

My Plans and Communications

Recognising Symptoms and Management

Within the last year of life

Actively dying

Who can help?

After Death

Appendices

EOL care for LD and Autism - HCPA



Questions



Exclusive retail discounts & wellbeing services



Save on shopping, invest in your wellbeing. Access hundreds of retail discounts plus wellbeing services including private healthcare*, 24/7 support service, gym discounts, financial tools, and a wellbeing centre

*fee applies

The Care Professional Academy



Upload your certificates, get more rewards...

Certificates will be uploaded to the Academy for you.
This is the only way you can access your certificates.
Keep adding to your certificates, the more certificates you add, the more points you get to move up the tiers.

Not yet signed up to the Academy?

Join here... careprofessional.co.uk

or scan the QR code



The Care Professional Academy



Upcoming education

- Oliver McGowan Tier 2 – Weekly
- Oliver McGowan Tier 1 (for non care providing staff) – 24th June
- Introduction to Positive Behaviour Support – 17th June
- Bipolar Awareness – 22nd June
- Schizophrenia Awareness – 22nd June
- Mental Health – Extended Knowledge – 24th & 25th June
- Depression care pathway - 1st July
- Understanding self-harm and suicidal ideation and intent – 13th July
- Substance Misuse Crisis Recovery and Implementing Wellness Plans – 22nd July

The HCPA Resource Library

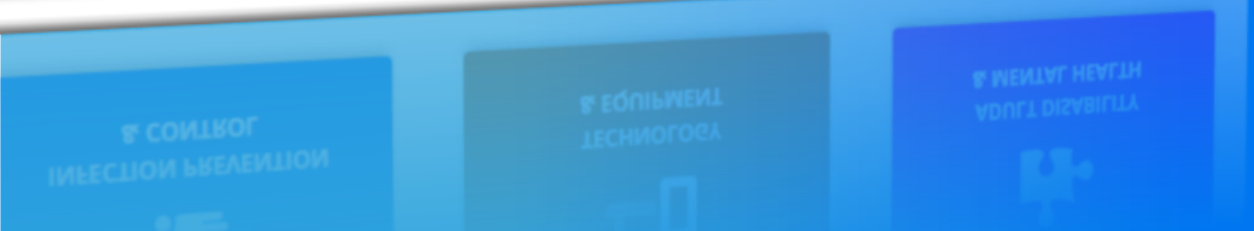
Everything you need, all in one place

Available to everyone, 24/7

Includes local and national resources, tools, guidance, policies, and contacts in a wide variety of areas

Perfect tool to support your business

hcpa.info/members-zone

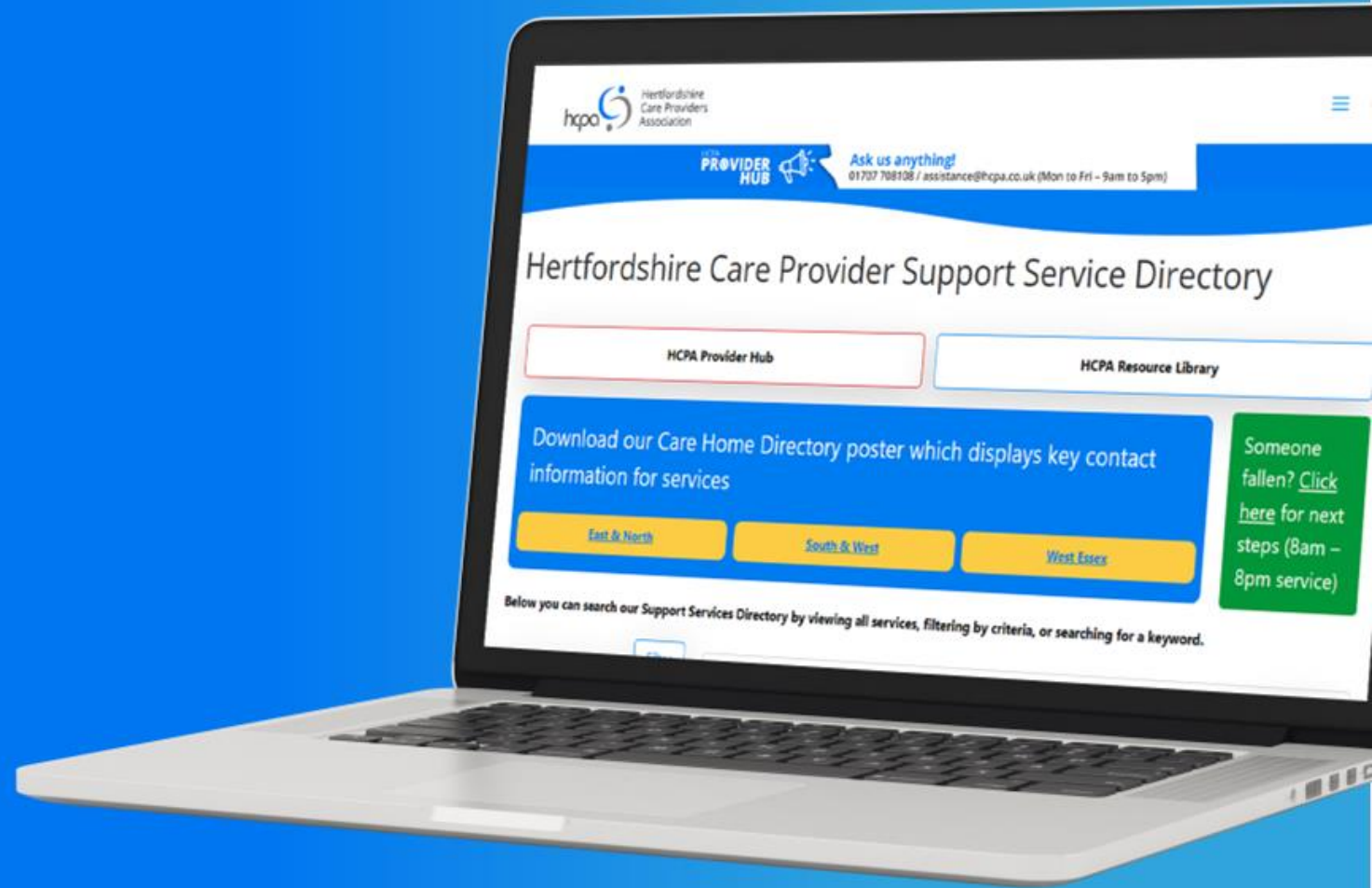


Support Service Directory

All the contacts you need, in one place

Up to date contact details for all the Hertfordshire support services you need

hcpa.info/supportservicedirectory



Thanks for joining us...

Before you go, please scan the QR code and leave us feedback

