



**End of Life Planning  
With  
Young People with Learning  
Disabilities  
&  
Their Families  
&  
Their Friends**

**EASY READ SUMMARY**

January 2018

**What is this project about?**



Many young people with learning disabilities have health problems that mean they will not live as long as other people.

This project helps you, your family and friends and your care-givers **to have conversations about end of life care.**

**What is end of life care planning?**



End of life care planning is a way of talking about, writing down and sharing your views as to **what you would like to happen** as you come to the end of your life.

**What does an end of life care plan include?**



**An end of life care plan could include:**

- Who you want with you as you are dying?
- Where you would like to be - for example, at home, in a hospice or hospital?
- What sort of treatment and care you would like?
- What sort of treatment and care you would not like?
- What music or belongings you would like with you?

**Who is an end of life care plan for?**



**The care plan is for you first** as you know what is best for you. An end of life care plan also **lets other people know your end of life wishes if you agree to share this.**

The 'other people' include your family, friends and care-givers in health and social care.

**What is good about an end of life care plan?**



It allows you to have your say about important decisions. It also allows you to share your views with people who care for you. Our approach is based on **values** such as those you can see in the bubble on the left.

**What is not so good about an end of life care plan?**

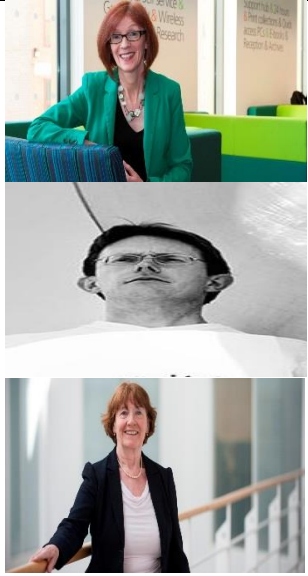


You might worry about **changing your mind** about what you want at the end of life.

This is **not a problem** as end of life care planning is a conversation that continues with you and your family, friends and care-givers. You can update your wishes at any time.

**We hope this summary will help you and your care-givers to start the conversation about your end of life care.**

You can read the full report and see the ADVANCE Toolkit at <https://www.surrey.ac.uk/international-care-ethics-observatory>

<p><b>Who ran and funded this project?</b></p>	
	<p>The people who worked on this project are: <b>Ann Gallagher</b> is Professor of Ethics and Care at the University of Surrey  Email: <a href="mailto:a.gallagher@surrey.ac.uk">a.gallagher@surrey.ac.uk</a>  <b>Matthew Peacock</b> is Research Fellow &amp; <b>Anne Arber</b> is Senior Lecturer at the University of Surrey</p> <p>The project was <b>funded by Health Education England working across Kent, Surrey &amp; Sussex</b> and is part of the <b>Intellectual Disabilities programme.</b></p>

### THE PROJECT TEAM WOULD LIKE TO THANK...

The Intellectual Disabilities programme of Health Education England working across Kent, Surrey & Sussex who commissioned and funded the project. We are also indebted to parents, practitioners, project participants and members of the Advisory Group who provided invaluable guidance which led to the development of the Toolkit & Workshop format - Thank You for your time, expertise and generosity. Members of the **Advisory Group** were:

- Jim Blair - Consultant Nurse Learning Disabilities - Great Ormond, Street Hospital, Associate Professor Learning Disabilities, Kingston and St. George's Universities
- Phil Boulter - Consultant Nurse for Learning Disabilities - Surrey and Borders Partnership NHS Foundation Trust
- Lizzie Chambers - Development Director - Together for Short Lives
- Craig Gannon - Medical Director - Princess Alice Hospice, Esher
- Faith Gibson - Professor of Child Health and Cancer Care – School of Health Sciences, Faculty of Health and Medical Sciences, Duke of Kent Building, Stage Hill Campus, University of Surrey, Surrey, GU2 7TE
- George Matuska - Transforming Care Programme Workforce Specialist Clinical Advisor, Learning Disabilities – Health Education Kent Surrey & Sussex
- Rhona Westrip - Programme Manager Learning Disabilities – Health Education Kent Surrey & Sussex

Thank you also the Ian Arber who edited the film free of charge. A special thank you to Rosie Field, Phil Boulter and Penny Smith who provided learning disabilities expertise to the video and workshops. Their positive collaboration is much appreciated.