

Living and Dying Well with Uncertainty - A Relative's Perspective of being a Carer

Uncertainty.... About my caring skills and knowledge

Help me improve my confidence, skills and knowledge by:

- Starting with what I know already
- Discussing common EOL symptoms and their management
- Demonstrating and practising practical caring skills
- Helping me access local and online services and information
- Giving my loved one and I the relevant information and allowing us to make our own care decisions

Uncertainty.... About my loved one's priorities

Help us discuss, agree and record:

- Overall aim for my loved one
- Priorities for living well
- Priorities for dying well
- Preferred priorities of care

At the Heart of every discussion and action

Uncertainty.... About my changing relationship with my loved one

Approach discussions with:

- Respect for our relationship
- A partnership of equality in caring for my loved one
- An acknowledgement of my knowledge of my loved one
- An acceptance that we don't need 'fixing'
- A 'walk alongside' approach

Uncertainty.... About the future

Help my loved one and I consider discussing and recording:

- Advance care planning documents
- Advance Decision and DNACPR if appropriate
- Lasting Power of Attorney for Finance and for Health and Wellbeing
- My role in supporting these decisions

Uncertainty.... About my caring role

Give me time to:

- Discuss my worries and concerns
- Explore my loved one's medical diagnosis and prognosis
- Listen to me with non-judgement
- Give me feedback on what I'm doing well

Uncertainty.... About my identity, needs and wellbeing

Encourage me to:

- Identify what's important to me and my priorities
- Take regular time out from caring
- Spend time doing things I enjoy and that replenish my energy
- Find ways of getting support from others – relatives, friends, neighbours and volunteers

Approach - Compassion, Equality, Empathy, Non-judgement