

PLANNING FOR ILL HEALTH AND END OF LIFE

There may be times in your life when you need to think about the consequences of you or a loved one becoming seriously ill and what this might mean particularly if that person is unable to make decisions for themselves. You may be thinking about this more during this COVID-19 outbreak. Naturally these can be difficult conversations to have at the best of times but planning ahead can save pain and heartache in the long run. At Action for Family Carers we believe it is really important for carers and their families to be involved in this process as much as possible.

Advance care planning

It can be an incredibly challenging and traumatic time if someone you are caring for is nearing the end of their life particularly if they lose capacity to make decisions about their care. Through a process called advance care planning anyone can record their preferences and wishes for their future care and treatment, which could include being cared for in a hospice or deciding they would prefer to be cared for at home. This is a voluntary statement and should be attached to a person's medical notes so they are easily accessible to anyone involved in caring for that person.

An advance care plan can include:

- where they want to be cared for when they are nearing the end
- where they would like to die
- who they want to have with them
- routines that are important to them
- anything that helps them feel comfortable and safe
- values such as religious beliefs

There is further information on the links below about advance care planning and other things to consider when caring for someone at the end of life:

<https://www.carersuk.org/help-and-advice/practical-support/when-caring-ends/end-of-life-planning>

<https://www.dyingmatters.org/page/planning-ahead>

Advance Decision (ADRT or 'living will')

Anyone can record their wishes with the support of a clinician regarding the treatment they wish to or not wish to receive – this is called an Advance Decision, sometimes known as an Advance Decision to Refuse Treatment (ADRT) or living will. This lets a person's family and health professionals know their wishes about refusing named treatments in specific circumstances if they are unable to make or communicate decisions themselves.

An advance decision is legally binding as long as it complies with the Mental Health Act and applies to the situation. There is further information on this and an online form on the link below:

<https://compassionindying.org.uk/choose-a-way-to-make-an-advance-decision-living-will/>

Hospice support

Your local hospice can offer a range of palliative care services, advice and support including counselling and bereavement support – please check with the hospice for current services as these may vary due to the Covid 19 pandemic. Caring for someone towards the end of the life or someone who has a life limiting illness can prove particularly challenging and can have a huge impact on a carer’s mental and physical wellbeing so we would encourage you to access the support provided by your local hospice.

- Farleigh Hospice, Chelmsford: 01245457300
- St Luke’s Hospice, Basildon: 01268 524973 / Bereavement support – 0333 4002358
- St Clare Hospice, Hastingwood near Harlow: 01279 773730
- St Helena Hospice, Colchester: 01206 845566
- Fair Havens Hospice, Southend: 01702 220350

Caring for someone at home who is dying

If you are caring for someone at home who is at the end of their life, **Marie Curie** is an invaluable source of support and information. You can call their support line for free and in confidence on **0800 090 2309** and also access an array of information on their website from knowing what to expect to looking after your own needs. The NHS link below is also a useful source of information.

<https://www.mariecurie.org.uk/help/support/being-there/end-of-life-preparation/home>

<https://www.nhs.uk/conditions/end-of-life-care/?tabname=what-is-end-of-life-care>

Practical support / equipment

There can also be many practical issues to consider when caring for someone in ill health at home. Naturally these will vary according to the person’s physical and mental condition. At Action for Family Carers we would recommend asking for an assessment of your home by an occupational therapist before purchasing any equipment – your GP can make a referral or you can contact your local council and ask for the Adult Social Care team.

Some equipment such as wheelchairs and commodes can be loaned from the British Red Cross. See <https://www.redcross.org.uk/get-help>

It may also be necessary to consider have adaptations carried out in your home, for example, to make washing and toileting easier or improving access into and around your home. The local authority has a Disabled Facilities Grant which could help pay towards the costs of any adaptations. You can contact your local housing department for information on how to apply.

Further information on practical support and equipment can be found here:

<https://www.carersuk.org/help-and-advice/practical-support/equipment-how-to-get-it>

Contact us:

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Planning for emergencies

It can be reassuring to know as a carer that if an emergency arises, for example, if you fall ill yourself, there will be someone to help should you need it. It may not be possible to turn to a family member particularly during the current Covid19 crisis or you may feel there is no one you can turn to. Carers UK advise carers to create an emergency plan for you and those you look after which can give you reassurance should the need arise in the future.

You would need to consider and include:

- details of the name, address and contact details of the person you look after
- who you and the person would like to be contacted in an emergency, for example, friends, family or professionals
- details of any medication the person you look after is taking and where it is stored
- details of any ongoing treatment they need
- details of any allergies
- details of their GP and pharmacy
- any care and support services they receive
- anything behavioural others need to be aware of
- any mobility challenges and mobility aids such as wheelchair or hoist

If possible talk about the plan with the person you care for and also with those you would like to be named as emergency contacts. Give people a copy of the plan or let them know where they can find it and ensure it is kept up to date.

You can also register on the government's helpline on 0800 028 8327 or visit <https://www.gov.uk/coronavirus-extremely-vulnerable> and you can ask for help in getting essential supplies or basic care needs. For support with care you could contact your local council.

For help with, for example, collecting prescriptions and other practical tasks you can refer yourself to the Essex Welfare Service which is staffed by volunteers.

<https://www.essexwelfareservice.org.uk/support-request>

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