



Do you look after someone who couldn't manage without your help?

Planning for the future

Advance care planning for future care

As a carer, there may come a time when you will need to consider the person you care for living with a serious illness or disability in the future and the consequence of becoming seriously ill or disabled. This could be at a time of ill health or as a result of a life changing event, or because it makes sense to plan ahead. If the person you are looking after is nearing the end of their life and the expectation is that their condition will deteriorate and they may lose capacity to make decisions about their care, they should be offered advance care planning. This is a voluntary process and allows the person you care for to record their wishes in advance and record their wishes for the end of life care they will receive.

Advance Care Plans (ACP) can also be made with a healthcare team when nearing the end of life. Advance Care Plans are used to record treatment and care wishes. They should be attached to medical notes and be easily accessible to those involved in their care.

The person you care for should include anything that's important to them in relation to their future health and care. The advance care plan can include:

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

Although an ACP isn't legally binding, it is good idea for the person you care for to make one to clarify and document what their wishes are. If the person you are looking after is near the end of life, it's a good idea to make one so that the people involved in their care know what's important

to them. Their healthcare team will try to follow their wishes and must take the plan into account when deciding what's in their best interests.

What is involved?

There are several things that can be considered to ensure that wishes are known and understood.

- **Discuss wishes for future healthcare.** The person you care for can discuss their wishes and preferences for care with you and their healthcare team. This can also include any wishes after death, such as organ donation.
- **Explore future care options.** These could be a care home or in a hospice for instance.
- **Discuss specific treatment choices.** The legal name is an Advance Decision to Refuse Treatment and it allows the person you care for to write down any treatments that they don't want to receive in the future in the event that they are unable to make or communicate decisions. It is also called a Living Will or an Advance Directive.
- The person you care for can appoint a Lasting Power of Attorney for Health and Welfare to make decisions about their care should they later become unable to make decisions.

How to make an Advance Care Plan

A plan document can be written by the person you care for, either with their own document or using a template such as the one provided by Dying Matters on their website www.dyingmatters.org. Further information is available on Alzheimer's Society website for advance decisions and dementia. www.alzheimers.org.uk/get-support/legal-financial/advance-decisions-dementia

Through this planning, the person you are looking after can also make an Advance Statement or Advance Decision about the treatment they wish or do not wish to receive. If the person you care for has made an Advance Decision, Advance Statement or Lasting Power of Attorney, this should be included as a note in their Advance Care Plan.

When completed, the person you care for should keep a copy and give a copy to anyone who is involved in their care.

They can change what they have written in their Advance Care Plan at any time, and it's a good idea to regularly review it to make sure that it still accurately reflects their wishes.

Best Interest meeting

Where the person you care for lacks the mental capacity to make decisions about their health and welfare and/or finances, any decisions made on their behalf must be made in accordance with the Mental Capacity Act 2005. This Act requires the decision-maker to make a decision that is in the adult's best interests, taking into consideration all circumstances.

This process focuses on a collaborative approach to decision-making. Best Interest assessments are therefore the responsibility of everyone involved in caring for the person, and the outcome is not based on any personal views.

A Best Interest decision involves any health and social care professionals involved with the adult's care, carers, family members and any other person concerned with the care of the adult. The meeting gives carers and family members the chance to express their wishes, along with any religious and cultural influences that need to be taken into account when making the decision. It also gives carers and family an opportunity to provide their view on what would be in the best interests of the adult concerned.

Best Interest decisions should only be taken in relation to specific decisions that an individual lacks the mental capacity to decide for themselves.

There may be situations where carers may wish to challenge a decision or need to find a way to resolve a dispute. This might happen if a carer thinks they have not been consulted where it would be appropriate, or a decision is made which the carer does not think is in the Best Interest of their friend or relative. Carers may involve an independent advocate, make a formal complaint, get advice from the Office of the Public Guardian or in the last resort go to the Court of Protection. The Court of Protection is a branch of the High Court, set up to protect people who lack capacity, and it can make determinations concerning any decision.

If you wish to challenge the decision or make a complaint, you can get advice and information from the following organisations:

- The advocacy people - www.theadvocacypeople.org.uk
- PoHWER - www.pohwer.net
- Healthwatch East Sussex - www.healthwatcheastsussex.co.uk
- Patient Advice and Liaison Service (PALS) on the NHS website - www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service.

Care provision

There are a number of options for care provision to consider and choose. Supported living services can help if residential care isn't an option and the person you care for is finding it difficult to cope at home. There are also other independent housing options including retirement villages and extra care housing.

Paid for care

If the person you care for is not eligible for financial assistance, they may choose to pay for care or support, e.g. a residential care home, nursing care home, care agency, a Personal Assistant or an activity in the day. The local council publicise a list of vetted and approved providers through their Support with Confidence scheme
apps.eastsussex.gov.uk/socialcare/athome/approvedproviders.

Care Agencies

An injury or illness may mean that someone you know or care for is finding it hard doing some everyday tasks. If the person you care for needs personal care, such as help getting showered and getting out of bed, home care agencies can provide home care support through paid carer staff they employ.

Personal Assistants

A personal assistant works with one or more individuals to help them with various aspects of their daily life, helping them to live as independently as possible.

You may also be considering other help such as help with pet care, shopping and preparing meals. Find out about services available here:
apps.eastsussex.gov.uk/socialcare/athome/approvedproviders.

Further information on the range of options for social care and support is available here: www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes.

Direct Payments

Care provision can be paid by Direct Payments for those that are eligible. These payments are an agreed amount of money that is given by East Sussex County Council so that you can organise and buy the care and support that is needed.

Direct payments are offered to provide care and support, and it is up to the person you care for if you want to use them. Direct payments are not

seen as income and have no effect on tax or benefits. They are just one way of receiving support from social care.

You can get direct payments if you are:

- a client of adult social care (anyone aged 18 or over)
- a carer of an adult, or
- a disabled child
- To be offered direct payments you first have to have a care and support needs assessment.

The biggest advantage of direct payments is the choice and control it gives you over your own care. You can employ the person or agency of your choice, pick which hours suit you and decide what tasks you want carried out.

Care for the Carers

Care for the Carers is an independent charity and the Carers Centre for East Sussex. We have been supporting and representing unpaid carers in East Sussex since 1989.

What do we do?

Our team of staff and volunteers can provide free practical and emotional advice – face-to-face, by telephone, or online. We can put you in touch with other carers, and help you navigate the range of services available locally. We also run support groups and events for carers in East Sussex and training for health and social care professionals and volunteers working with carers.

Care for the Carers represents carers and raises awareness of caring, working with a variety of local communities, organisations and service providers to build a carer friendly East Sussex.

All our work is developed with carers, and in response to their expressed needs reflecting local and national strategy, legislation, research and best practice. We work with carers so that they are empowered and can have a say in the policies and services that affect them.

During the Coronavirus pandemic, we are here to support all carers and offering our services by phone or online.

How to contact us

Call our Carers Hub on 01323 738390, Monday to Friday, 10am to 5pm to speak with one of our team of dedicated support workers.

Email us: info@cftc.org.uk

Text us: 07860 077300

Request a call back using the contact details above.

More information and carer resources at: www.cftc.org.uk.

No one left to care alone

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