



Action for Carers Supporting someone at the end of life

A guide for unpaid carers



Introduction

This checklist has been created through listening to carers who have experienced caring for someone at the end of their life. It is a tool for you as a carer to use to help you through this very difficult time.

The information is there to guide and prompt you through the many different areas of support and care that you and your loved one may experience. It also suggests support from different organisations which we hope you will find helpful.

Please remember that we are here for you so please call us on 0303 040 1234 or email CarerSupport@actionforcarers.org.uk

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Action for Carers' Support

Carer Helpline

We are here for when you need us.

If it matters to you, it matters to us. Carer Helpline Advisors are here during the week to speak to you and provide information, advice, support, or just to listen.

Please call us: 0303 040 1234, CarerSupport@actionforcarers.org.uk

Carer Support Advisors

If you need help related to your caring role, we can put you in touch with one of our Carer Support Advisors working in your area.

They can help in many ways, including:

- Information on which benefits to apply for
- Emotional support
- Signposting to further sources of help

Moving and Handling Service

As a carer, your role may include helping someone move about. We can put you in touch with our Moving and Handling service which provides safe solutions for carers who carry out moving and handling as part of their role.

The team offer information, advice, training and support to help carers prevent potential injury to themselves or the person they care for – adults and children. Whether it's simple tips, or discussing more specialised equipment that will help, our team can advise.

Hospital Carer Support Advisors

If you need support when your loved one is in hospital, our Hospital Carer Support Advisors, working across Surrey, can help. See pages 6-7.

Action for Carers' Workshops & Events

Action for Carers runs multiple events and workshops throughout the year. This includes end of life related workshops, which will be listed on our website, such as:

- Anxiety and Loss Workshop
- Anticipatory Grief

If there is a particular area of end of life care which you would like to have more information or training about, then please let us know.

Looking after you

Looking after yourself at this difficult time is very important and one we appreciate is hard to do as a carer.

We have online and face-to-face wellbeing events which you are welcome to join and find time for you. If you need assistance with finding or funding any replacement care to attend an event then please speak to us.

All our events and groups are in the newsletter, regular email updates and on our website. Please join us!

How to book on to our events, workshops and support groups

Booking is essential. You can book in three ways:

- Visit our website events section
- Call us on 0303 040 1234 option 1
- Or email CSAdmin@actionforcarers.org.uk

Once booked, we'll send instructions.

Hospital Carer Advisors

Having the person you care for in hospital can be a difficult and stressful experience

Our Hospital Carer Support Advisors are there to help. We have staff at the following hospitals: East Surrey, Epsom, the Royal Surrey County and Ashford and St Peter's.

Wide-ranging support

Our Hospital Carer Support Advisors work closely with hospital staff to identify carers and to support you whilst your loved ones are in hospital.

- They can help bridge communication gaps between you as the carer and hospital staff, including advocacy when appropriate.
- They can offer you advice and information as well as provide emotional support.
- They can signpost carers and their loved ones to support from other organisations.
- They can guide carers through the hospital discharge process.
- They can refer you back to our Carer Support Advisors, once back in the community.

If you need support whilst the person you care for is in hospital or need help with any hospital related issues then please give us a call so we can put you in touch for support.

Feel free to contact the Advisors directly (see opposite), or call ACS on 0303 040 1234 or email CarerSupport@actionforcarers.org.uk



Hospital Carer Advisors



East Surrey Hospital

Katie Davey

Monday to Friday

07989 402663

Katie.Davey@actionforcarers.org.uk



Epsom General Hospital

Michele Moore

Mondays, Wednesdays, Fridays

07736 561978

Michele.Moore@actionforcarers.org.uk

and

Tamzin Ede

(Team manager) Thursdays

07736 561976

Tamzin.Ede@actionforcarers.org.uk



Royal Surrey County Hospital

Naheeda Majid

Monday to Friday

07850 515457

Naheeda.majid@actionforcarers.org.uk



Ashford and St Peter's Hospital

Sam Caine

Monday to Friday

07989 402764

Sam.Caine@actionforcarers.org.uk

What end of life care involves

End of life care is support for people who are in the last months or years of their life.

End of life care should help the person you care for live as well as possible and die with dignity. The people providing their care should ask them and you about their wishes and preferences, and take these into account as they support any care plan. They should also support you as the carer.

Who provides end of life care?

Different health and social care professionals may be involved in end of life care, depending on the needs of the person you care for. For example, hospital doctors and nurses, your GP, community nurses, hospice staff and counsellors may all be involved, as well as social care staff, chaplains (of all faiths or none), physiotherapists, occupational therapists or complementary therapists.

What is palliative care?

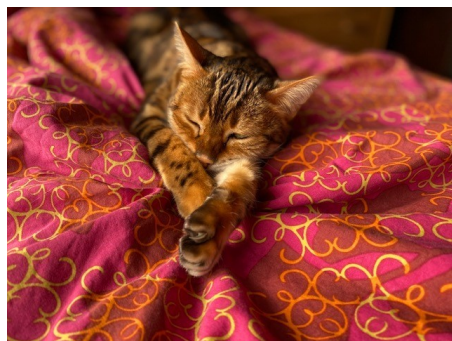
End of life care includes palliative care. If the person you care for has an illness that cannot be cured, palliative care makes them as

comfortable as possible, by managing their pain and other distressing symptoms. Palliative care is not just for the end of life – you may receive palliative care earlier in your illness, while you are still receiving other therapies to treat your condition.

Who provides palliative care?

Many healthcare professionals provide palliative care as part of their jobs. An example is the care you get from your GP or community nurses.

Some people need additional specialist palliative care. This may be provided by consultants trained in palliative medicine, specialist palliative care nurses, or specialist occupational therapists or physiotherapists.



What end of life care involves

When does end of life care begin?

End of life care should begin when it is needed and may last a few days, or for months or years.

People in lots of different situations can benefit from end of life care. Some of them may be expected to die within the next few hours or days. Others receive end of life care over many months.

People are considered to be approaching the end of life when they are likely to die within the next 12 months, although this is not always possible to predict. This includes people whose death is imminent, as well as people who:

- have an advanced incurable illness, such as cancer, dementia or motor neurone disease
- are generally frail and have co-existing conditions that mean they are expected to die within 12 months
- have existing conditions if they are at risk of dying from a sudden crisis in their condition
- have a life-threatening acute condition caused by a sudden

catastrophic event, such as an accident or stroke

The National Institute for Health and Care Excellence (NICE) has published guidance on the care of dying adults in the last days of life. This guidance covers how to manage common symptoms, as well as dignity and respect for the dying person, their relatives and carers.

[End of life care for adults](https://www.nice.org.uk/guidance/ng142/resources/end-of-life-care-for-adults-service-delivery-pdf-66141776457925) [\(nice.org.uk\)](https://www.nice.org.uk/guidance/ng142/resources/end-of-life-care-for-adults-service-delivery-pdf-66141776457925)

<https://www.nice.org.uk/guidance/ng142/resources/end-of-life-care-for-adults-service-delivery-pdf-66141776457925>

How do I find out about end of life services in my area?

If the person you care for is approaching the end of their life and you want to find out about the care and support available, your first step is to speak to your GP or doctor in the hospital.

And you can call us at Action for Carers and we will tell you about the services and support available locally.

When You are First Informed

When the person you care for, and you as their carer, are first informed about a diagnosis or end of life condition it's an emotional and confusing time. Please use the checklist to help you, and remember we are here for you every step of the way.

- Do you have all the facts and information about the diagnosis to understand the illness or condition? Use the prompt sheet p11-12.
- Do you need to create an End of Life Care Plan. Who could help?
- Have you shared this plan with the medical team, relatives, GP. See page 14.
- Have you set up a Lasting Power of Attorney for finances and health? Should you activate this now?
- Have you updated any relevant insurance paperwork?
- Have you informed the Department of Work and Pensions (DWP) about changes in health needs or applied for benefits, e.g. Personal Independence Payment (PIP) for special circumstances? Action for Carers can help with benefit applications etc.
- Log all their passwords for accounts and online access in one place and keep it in a safe place.
- Do you need to be joint signatory on any bank accounts?
- Create a 'where to find' list for family and other people helping with care, e.g. emergency plan/medication/equipment/phone nos.
- Contact family and friends to organise any support e.g. sitting with your loved one, shopping, transport etc.
- Equipment – do you have the correct equipment at home to care? Ring 0303 0401234 to ask for a referral to Action for Carers' Moving and Handling service.
- Do you need support for any children? Our service for under 18s, Surrey Young Carers, can help.

Other issues to address: ?

Receiving the Diagnosis

Get all the information you can.

- What is the exact diagnosis? What stage is their illness at?
- Is there a projected time-frame for life expectancy?
- Is there any treatment available and if so, what are the pros and cons?
- How much quality and time would treatment add onto their life if this is an option?
- Does the person I care for have mental capacity?

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- Will there be any medication needed and is there a review of this medication?
- What is duration will the medication be needed for?
- Does the medication have any side effects and if so what are the side-effects?
- Who will be overseeing the medication and ensuring that any adjustments are made as and when needed?

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Receiving the Diagnosis

- Who is the main person that will be overseeing all medical care?
- Who will be the person overseeing all of the healthcare for the person I care for and liaising between professionals?
- If needed will a referral be made to the District Nursing Team?
- Who do I call in an emergency out of hours if the person I care for is needing medical attention, but not a paramedic?
- What referrals are you intending to make and reason for referral?
- Will a referral be made to the local hospice?
- How can the hospice support the person I care for and me as the illness progresses?

Notes



Advance Care Planning

Advance Care Planning is the process of making decisions about what kind of care the person you care for would like to have in the future.

It can be helpful as it makes sure that everyone knows what matters to them and you. Here, we talk about what you can include in an advance care plan, how it will be used, and how you can make one.

What to include in an advance care plan

Start by asking the person you care for the question, 'what matters to you?'. This can help you both plan for the future. Knowing what matters most and sharing their wishes can help them feel supported in any decisions. The advance care plan can include any decisions about how they would like to be looked after.

Where would they like to be looked after in the future, and in their final days?

- any spiritual or religious beliefs they would like taken into account
- who they want to spend time with
- who their doctors or nurses should talk to if they don't have capacity to make decisions
- the name of the person they have appointed to make decisions on their behalf if they're unable to make them (lasting Power of Attorney)
- how they would like practical matters dealt with, such as the care of a pet

What would they like to happen to their body after they die?

Having conversations with the healthcare team and you as the carer will help everyone understand what's important and what is possible.

Advance Care Planning

How to make an Advance Care Plan

The doctor or nurse might suggest that you and the person you care for have a conversation about their future care. But you can begin the conversation with them at any time.

Ask your healthcare professional for an advance care planning form. Some NHS Trusts, GP surgeries and charities like Marie Curie will have these available on their websites. Plans need to be reviewed.

[Advance care planning \(mariecurie.org.uk\)](https://www.mariecurie.org.uk)

<https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/advance-care-planning>

Telling people about your Advance Care Plan

Once it is decided what to have in the plan, give a copy to the people involved in their care and your family or friends.

Your doctor or nurse can tell you how to make sure other health and social care professionals know about their advance care plan. They might be able to create an electronic record of the plan that could be accessed by hospital staff or out-of-hours doctors. These services vary depending on where you live.

Please give family or other people involved in the care a copy or tell them where to find the advance care plan.



Other Issues to Consider

- Do you have a Lasting Power of Attorney for health and wellbeing and finances?
- Is the Lasting Power of Attorney registered? Do you know how to register it? Contact Action for Carers if you need help with LPAs. [Office of the Public Guardian - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/organisations/office-of-the-public-guardian)
<https://www.gov.uk/government/organisations/office-of-the-public-guardian>
- Advanced Care Plan: Talk to the ward staff about the plan and ask to be involved in creating it.
- Do you need to find out about benefits you may be entitled to?
- If the person you care for lives on their own, do they need a personal alarm to alert people if they fall or are in trouble?
- Are they entitled to a Blue Badge? Action for Carers can support with this application.
- Do you need respite support and what support might there be when the person you care for is back home? We can advise. You can for example be referred to Crossroads Care for EOL support
- Is the person you care for eligible for Continuing Health Care funding? Ask Action for Carers for the booklet 'NHS Continuing Health Care – A guide for Surrey Carers' for more information.
- Is the person you care for self-funding? Contact Action for Carers to find out how you can find support.
- Have you been referred for a Carer Assessment before the person you care for is discharged from hospital? Have you been asked if you are willing and able to carry on caring if the person you care for is returning home? Our Hospital Carer Advisors (see page 6-7), or Helpline team, can advise and support with the discharge process.

Planning for Emergencies

You can plan what the person you care for would want to happen in an emergency, for example if they become suddenly unwell with an infection or a stroke.

One way to plan for this is by using the ReSPECT process (Recommended Summary Plan for Emergency Care and Treatment).

The ReSPECT process helps people decide what care they would like if they have a medical emergency.

Discuss the options with the person you care for and their doctor or nurse and those important to them, in case there is a medical emergency and they are unable to say what they want.

You could discuss a DNACPR decision, and whether they would want to go to hospital for treatment.

Write their preferences in a ReSPECT plan so that the healthcare professionals looking after them know what they want.

Read more about ReSPECT: <https://www.resus.org.uk/respect>

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ReSPECT Recommended Summary Plan for Emergency Care and Treatment

Full name: _____
Date of birth: _____
Address: _____
NHS/CHI/health and care number: _____

1. This plan belongs to:
Preferred name: _____
Date completed: _____

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition
Summary of relevant information for this plan including diagnoses and relevant personal circumstances: _____

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer): _____

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 Yes No

3. What matters to me in decisions about my treatment and care in an emergency
Thinking as long as possible about matters most to me: _____
Quality of life and comfort matters most to me: _____

What I most value: _____
What I most fear / wish to avoid: _____

4. Clinical recommendations for emergency care and treatment

<input type="checkbox"/> Prioritise extending life clinician signature: _____	<input type="checkbox"/> Balance extending life with comfort and valued outcomes clinician signature: _____	<input type="checkbox"/> Prioritise comfort clinician signature: _____
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Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital or receiving life support) and your reasoning for this guidance: _____

CPR attempts recommended Adult or child
clinician signature: _____

For modified CPR, Child only, as detailed above
clinician signature: _____

CPR attempts NOT recommended Adult or child
clinician signature: _____

www.respectprocess.org.uk

Hospices in Surrey

Hospices traditionally provide care for those with cancer. However, some hospices are now providing end-of-life care for those suffering from other forms of terminal illness.

Hospice care seeks to improve the lives of people living with a progressive and life-threatening condition. By offering high-quality, specialist palliative care it helps them to live as actively as they can to the end of their lives, however long that may be. It not only takes care of people's physical needs but looks after their emotional, spiritual and social needs as well.

Wide variety of support

Hospices provide care in a number of different places including people's own homes, day care and inpatient units. They will often also provide support in local care homes and other community settings. People can use hospice care at any stage of their illness, not just at the very end of their life. There are hospices for adults, and for children and young people.

Hospice care also supports carers, family members and close friends, both during a person's illness and during bereavement.

Surrey hospices

Phyllis Tuckwell Hospice: 01252 729400, Waverley Lane, Farnham

Princess Alice Hospice: 01372 468811, West End Lane, Esher

Woking and Sam Beare Hospice and Wellbeing Care:

01483 881750, Goldsworth Park Centre, Woking

Same Beare (Community Team): 01932 598385,

Woking (Community Team): 01483 881755

Shooting Star Chase: 01483 230960, Christopher's Children's Hospice, Old Portsmouth Road, Artington, Guildford

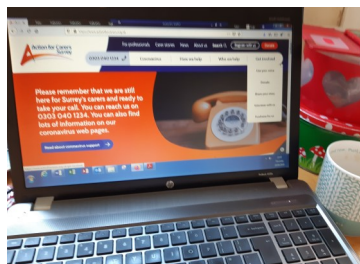
St Catherine's Hospice: 01293 447333, Grace Holland Avenue, Pease Pottage, Crawley

Useful Websites and Local Resources

Here are some helpful websites to find further support and information. Please use the space opposite to record any other support you find.

Action for Carers — Surrey's charity for unpaid family and friend carers, providing support, advice, events, information and more.

www.actionforcarers.org.uk



Carers Trust UK

www.carersuk.org/help-and-advice/practical-support/end-of-life-planning/

Surrey County Council

www.surreycc.gov.uk/adults/choosing-the-right-care/end-of-life

Surrey Heartland's End of Life Strategy

www.surreyheartlands.org/download.cfm?doc=docm93ijjm4n993.pdf&ver=815

NHS's Guide to End of Life Planning

www.nhs.uk/conditions/end-of-life-care/

Hospice UK

www.hospiceuk.org/information-and-support/your-guide-hospice-and-end-life-care/planning-ahead

The Good Grief Trust

A national charity offering practical, financial information and support.

www.thegoodgrieftrust.org

Alzheimer's Society

Support for when a person with dementia is nearing the end of life.

www.alzheimers.org.uk/get-support/help-dementia-care/recognising-when-someone-reaching-end-their-life

Further Organisations

Organisation

Email/phone number

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Organisation

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Action for Carers Surrey

We provide information, advice and support for carers of *all* ages, right across Surrey.

Our support includes benefits advice, advocacy, guidance on moving and handling, workshops, events, support groups, drop-in Hubs throughout Surrey, resources and more — giving carers a little time out and helping them feel less stressed, and more in control.

We have specialist support for young carers and also provide training and support for professionals working with carers.

Find out more at www.actionforcarers.org.uk

THANK YOU to the carers who have contributed to this booklet.

If there is something we should add, or if you've any comments at all, please let us know.

Email CarerSupport@actionforcarers.org.uk.

Action for Carers Surrey

Call us on 0303 040 1234; email
CarerSupport@ActionforCarers.org.uk

www.actionforcarers.org.uk

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