

**Do you help look after someone or
give them support?**

If so, you may be a carer



Information to help carers, family and friends

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Some of the team involved in the production of this handbook

Introduction

This handbook has been produced in collaboration with Hertfordshire unpaid carers, local NHS trusts and voluntary carer organisations to combine a variety of information from a range of sources into one booklet for carers. Thank you to everyone involved, especially the carers, for all the time and expertise they shared for this handbook to reflect what they thought was important for carers to know.

Produced by Jodie Deards, Carers Lead, East and North Hertfordshire NHS Trust.

Edited by Maria Rushton, Patient Information Co-ordinator, East and North Hertfordshire NHS Trust.

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- Inclusion and Engagement Team Manager, Hertfordshire Partnership University NHS Foundation Trust
- Carers Lead, West Hertfordshire Hospitals NHS Trust
- Engagement Manager and Carers Lead, Hertfordshire Community NHS Trust
- Admiral Nurse, East and North Hertfordshire NHS Trust
- Learning Disability Matron, The Princess Alexandra Hospital NHS Trust
- Crossroads Care, Hertfordshire North
- Carers in Hertfordshire
- Hertfordshire Parent Carer Involvement Network
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For carer resources specific to each organisation, please contact them directly.

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Do you help look after someone or give them support? If so, you may be a carer...

You are a carer if you provide unpaid help and support to a family member, friend or neighbour who would otherwise not be able to manage without your help.

Every day 6,000 people in England become carers. For some it's sudden, someone you love is taken ill or has an accident. For others, caring creeps up unnoticed, your parents can't manage on their own any longer, your partner's health gets gradually worse.

Many people do not see themselves as a carer. They are simply someone's parent, partner, child, friend or neighbour. Whether or not you think of yourself as a carer, if you help support someone, then you may find this information useful.

The person you care for may have a physical or learning disability, dementia, mental health problems, misuse drugs or alcohol, or may be sick, elderly and/or frail.

It may be that the person you are visiting in hospital at the moment may need extra support or assistance from you as a result of their hospital admission.

The person may live with you or elsewhere, they may be an adult or a child, but if they rely on you for support, then **you are a carer**.

This handbook is designed for **adult carers**. It provides information about the help and support that is available to you, what to expect with a hospital admission, and how to ensure a safe and secure transition back to the community.

If you are a **young carer** (under 18 years) you may still find this handbook helpful. However, for support and advice specific for your needs, contact your local carer support organisation (see page 18) who will be able to guide you. Alternatively, you can download the **Young Carers in Herts App** on your smartphone.

Our Commitment

From the NHS trusts in Hertfordshire and West Essex

It can be difficult to discover that someone you love and care for has a significant health problem, or that their health condition has deteriorated.

Carers often provide emotional support as well as practical help. Many carers find their role extremely rewarding and would never change their situation. However, caring can be very demanding, stressful, and at times feel completely overwhelming.

The NHS trusts across Hertfordshire and West Essex accept that they have a responsibility to recognise the needs of all carers, particularly in relation to accessing information, advice, education and support to enable you to cope. We welcome the expert knowledge that carers possess about the person they care for and recognise the need for partnership working with them. As a carer, you should feel valued, respected and confident when you enter the hospital environment.

Single Carer Pathway

All NHS health services in Hertfordshire are working towards a single carer pathway so that you can feel supported and valued. The pathway is described below:



(Carer Pathway co-produced by Hertfordshire Partnership University NHS Foundation Trust — 2016)

Throughout this handbook, the pathway symbols above are linked to each section.

Attending appointments or an admission to hospital

If the person you care for is coming to hospital, it is important that you let hospital staff know as soon as possible that you are their carer. It is also important to speak to staff if you have any worries or concerns about your caring role, especially if you feel you need additional support or assistance.

Carer support

The hospital recognises the vital role carers play in the health and wellbeing of those they care for. We are committed to ensuring that a partnership approach to care is adopted. The carer's role, knowledge and understanding of the patient's needs, will be recognised and taken into account when planning their care, treatment and discharge.

Carers are welcomed onto the wards and encouraged to continue their caring role if they wish. This can include helping with meals, washing, dressing and offering support and reassurance to the person you care for. Carers will be offered flexible visiting and you can stay overnight with the person you care for, if appropriate. Please discuss your needs with the nurse in charge.

Lister Hospital operates a Carers' Passport scheme (as pictured below); The Princess Alexandra and Watford General Hospital have a Carers' Card. Both the Carers' Passport and Card help staff identify you as having a caring role and ensure you are included in all discussions about the person you care for and their treatment plan and discharge.

The Carers' Passport and Carers' Card entitles you to some discounts **within the hospital**, e.g. restaurant. Please ask ward staff for more information.

You can also apply for a Carers' Passport/Card from your local carer support organisation (see page 20).



What is needed for a hospital admission?

Please ensure the person you care for brings the following with them:

- Any medication they are currently taking. A list of these with dosage details etc., is useful (see page 22, 'Message in a Bottle' scheme)
- Pyjamas or nightdress and a dressing gown
- Comfortable casual clothes for the day
- Shoes or slippers
- Face cloth and towel
- Toiletries - soap, deodorant, toothbrush, toothpaste, comb or hairbrush, shaving equipment (if required)
- Glasses, hearing aid and dentures - please also bring a named container for each to ensure safekeeping
- Hospital letter (if you have one) and any other medical information

Wireless internet access

Our hospitals have free Wi-Fi service which will allow patients and visitors to access emails and search the internet. Simply find the 'Free Hospital Wi-Fi' or 'NHS Wi-Fi' network on your device. You will not be able to stream videos or download large files.

Car parking

If you are visiting for more than a few days, there are discounts or special permits available. Please ask the staff on the ward about this.

What to do if you have any concerns

To help resolve your concerns as quickly as possible, please speak to the nurse in charge or ask to speak to one of our matrons. They will try to resolve these concerns and answer any questions straight away.

You can also contact the Patient Advice and Liaison Service (PALS). PALS provide advice and support for patients, relatives and carers. They are here to listen to you and help resolve concerns and queries. The hospital reception desk will provide you with contact details for PALS or you can refer to the hospital website.

Ward Information

Welcome

Involvement

Infection prevention

Having clean hands helps prevent infections spreading. Please wash your hands on arrival and when leaving the ward, using either the hand sinks or alcohol hand foam provided at the entrance of every ward.

Visiting hours

The hospital has open visiting hours for carers. Please let the ward staff know that you are a carer and planning to stay for extended periods, or if you wish to visit outside of the normal visiting hours.

Estimated date of discharge (EDD)

Within 24 hours of admission, the medical team will set a date for when they expect treatment to be complete and the patient ready for discharge. The patient and carer/family should be told this date. If there is a change in the EDD due to a change in condition, the patient and carer/family should also be informed. The EDD is reviewed every day. If you do not know the EDD, please ask your allocated nurse.

Allocated nurse

A nurse is allocated to each patient on the ward at the start of each shift. The nurse's name is written on the whiteboard above the bed. This is the nurse you should speak to about the treatment plan for the person you care for.

Legal Terms in Healthcare

Assessment &
Support

Involvement

Consent

This means the person you are caring for has agreed for you to know what is wrong with them and what treatments will be given.

The person you care for will need to inform the hospital staff and GP surgery that they give their consent for you to be informed about their medical condition. This consent can then be added to their hospital and GP medical records for future reference.

When consent is refused/common sense confidentiality

When the person you care for has refused or not given permission to healthcare professionals to share information, we are unable to tell you exact information about their care. We can only talk to you about what you already know about the person you care for; staff can only give you general information.

As a carer, you know the person you care for the best. You know if they are becoming unwell, or if things are not quite right, sometimes even before anyone else realises. Any information you have about the person you care for, such as their general health, illness, what they usually can and can't do, and their mental state, is really important.

Even if the person you care for has not given consent for you to know what the healthcare professional decides, you can still tell them information about the changes that have been occurring and they can talk in general terms to you about what you might expect in someone with the same condition on the same treatment.

Making decisions and the Mental Capacity Act (MCA)

The Mental Capacity Act (MCA) is for everyone over the age of 16 years living in England and Wales who are unable to make their own decisions or lack the capacity to do so. If someone is confused or unconscious, for example, the MCA would be used. It is there to protect a person's right to be able to make decisions, now and in the future. These decisions are about health and finance.

Mental capacity is the ability to make your own decisions and every person is assumed to have the capacity to make their own decision. We can divide these decisions into small decisions and big decisions. A small decision could be choosing what to wear today, a big decision would be deciding on medical treatment.

When you make a decision you need to be able to:

- Understand all the information you need to make that decision
- Use or think about that information
- Remember that information
- Communicate your decision to someone else



Communicating your decision is not just telling someone. You can communicate in any way, such as using diagrams or pictures. Making an unwise decision is different to not having the capacity to make a decision. If you think the person you care for does not have the capacity to make big decisions, please discuss this with your allocated nurse.

If the person you care for is worried that they may lose mental capacity in the future, and want to ensure their wishes are respected, they can arrange for a Lasting Power of Attorney.

Lasting Power of Attorney (LPA)

Don't assume, if the person you care for loses their mental capacity, that you would automatically be able to deal with their finances and/or make decisions about their healthcare, even if you are their legal next of kin. This is not the case. Without a LPA, you won't have the authority. Once they lose capacity, the person you care for will be unable to complete a LPA.

A LPA lets a person choose someone they trust to act on their behalf. This person is referred to as the **attorney**. The decisions the attorney can make can be limited, or have conditions added.

There are two different types of LPA:

- **Health and welfare LPA**

A health and welfare LPA allows the attorney to make decisions on a person's behalf about their health and welfare, if there comes a time when they are unable to make these decisions. A health and welfare attorney could make decisions about the person they are acting on behalf of, for example, where they live or about day-to-day health and medical care etc. If decisions are being made on a person's behalf, the LPA will need to be shown to the relevant healthcare professional.

- **Property and financial affairs LPA**

Once registered, a property and financial affairs LPA becomes active straight away, even if the person who appointed the attorney is still able to deal with these things by themselves. This can include paying bills, collecting income and benefits, or selling a property.

A LPA can only be used after it has been registered at the Office of the Public Guardian. There is a cost associated with registering a LPA and receiving the document.

For more information contact your local carer support organisation (see page 18) or visit www.gov.uk/government/publications/make-a-lasting-power-of-attorney

Get up, get dressed, keep moving

When they are well enough, we will encourage the person you care for to get out of bed, change out of their pyjamas and move around.

What can you do to help?

- Bring a change of loose, comfortable day clothes for them
- Take home any items that need washing as the hospital is unable to do personal laundry
- Let staff know if you wish to help the person you care for wash, dress and walk to the bathroom
- Encourage the person you care for to keep moving and stay active
- Bring footwear that is closed back and non-slip
- Ask staff if the person you care for does not have the right equipment to help them move about safely

The facts... For every 10 days of bed rest, the equivalent of 10 years of muscle ageing occurs in people over 80 and building this muscle strength back up takes twice as long as it does to deteriorate. This can be the same for all patients, whatever their age. A loss of muscle strength can affect climbing the stairs, getting out of bed and standing up from the toilet on their own. It can be the difference between going home or requiring supported care. Muscle loss can be reduced by encouraging patients to get up, dress for the day, eat meals at the bedside or in a dining area, use the toilet instead of a commode and generally participate in normal daily life as much as possible.

 <p>Closed back and grippy slippers are critically important to allow safe walking.</p>	 <p>Wash and dress yourself if you are able and wear your own clothes where possible.</p>	 <p>Let us know if you feel light-headed on standing, so we can measure your blood pressure.</p>
 <p>Sitting out of bed helps your recovery more than lying in bed.</p>	 <p>Do you have the right equipment to help you move about safely? If not, ask us.</p>	 <p>We encourage you to walk to the toilet but please use the call bell if you need assistance.</p>

A Guide to Uniforms

Involvement

Staff you are likely to meet during your visit to Lister Hospital.

Other hospitals, such as West Hertfordshire Hospitals NHS Trust, The Princess Alexandra Hospital NHS Trust and the Hertfordshire Community NHS Trust have different uniforms, please see their website or ward posters for more details.



 <p>Clinical Support Worker (CSW)</p> <p>Trained to help nurses look after patients, give personal care and make sure patients are comfortable.</p>	 <p>Staff Nurse</p> <p>A qualified nurse who gives treatment, looks after patients and monitors their recovery.</p>	 <p>Junior Sister</p> <p>A qualified nurse who supports the Senior Sister in treatment and monitoring of patients and helps organise the ward.</p>
 <p>Senior Sister - Charge Nurse</p> <p>A qualified nurse who oversees the ward and its staff making sure that all patients receive the care and treatment they need.</p>	 <p>Matron</p> <p>A senior qualified nurse who manages a group of wards making sure patients receive high quality care and treatment.</p>	 <p>Specialist Nurse</p> <p>A nurse who has advanced knowledge in an area of nursing and supports people with specific conditions.</p>
 <p>Nursing Services Manager</p> <p>A senior qualified nurse who leads all the nursing staff in a team.</p>	 <p>Housekeeper</p> <p>Provides food and drink for patients and helps with administrative tasks on the ward.</p>	 <p>Ward Clerk</p> <p>Welcomes patients to the ward and helps the nursing staff with administrative tasks on the ward.</p>
 <p>Occupational Therapist (OT)</p> <p>Helps patients become more independent in daily activities such as washing and dressing, and helps with plans for going home.</p>	 <p>Physiotherapist</p> <p>Assess physical problem of patients caused by surgery, illness, injury, disability or ageing and plan exercises to improve movement.</p>	 <p>Phlebotomist</p> <p>Takes blood samples from patients.</p>
 <p>Training Nursing Associates (TNA)</p> <p>Provide basic nursing care to patients as they train to become a nursing associate.</p>	 <p>Pharmacist</p> <p>Makes sure that patients receive the right medication and give advice to patients about their medicines.</p>	 <p>Cleaner</p> <p>Makes sure that the ward is kept clean.</p>
 <p>Student Nurse</p> <p>Work on the wards while studying to become a qualified nurse. They carry out tasks on the ward to help the nursing staff.</p>	 <p>Porters</p> <p>Assist with transfer of patients and equipment around the hospital.</p>	<p>Other Staff you may see on the ward</p> <p>Doctors and Consultants wear their own clothes and will have a name badge. Other staff who wear their own clothing include social workers, dietitian and speech and language therapists.</p>

Every member of staff should wear their name badge and introduce themselves to you, saying 'hello my name is'. If this doesn't happen then please ask, 'who are you and what do you do?'

Discharge from Hospital

Involvement

Transition

In most cases, the length of stay in hospital is defined by the type of procedure or treatment that is required, and whether any extra support will be needed at home.

What should happen before the person I care for is discharged?

The carer should be involved at all stages of planning for discharge. If you have any concerns about carrying on with your caring role, or have worries about coping with some of the tasks that you'll need to do after discharge from hospital, please speak to the nursing staff as soon as possible. It is important to let them know how you feel so that they can give you, and the person you care for, the support you need.

Discharge planning involves:

- Estimating the date of discharge (see page 5) and sharing this with the carer and/or family
- Reviewing the person you care for to determine when they are '**medically fit**' to be discharged. This means that the medical treatment has been completed. An assessment will then be done to determine what social support, if any, is required to enable discharge
- Discussing and agreeing practical preparation for the discharge home. If extra social support is required to help you to continue to care, a social worker will discuss your requirements and assess the needs of the person you care for
- Ensuring that any equipment or alterations to support safe discharge are in place before discharge takes place
- Providing the carer with sufficient information to safely care for the patient, including information on medication, equipment, patient handling and changes in the patient's condition that affects the patient's care needs

If you feel you need to discuss your support needs further, speak to your allocated nurse.

The **Discharge Lounge** is where patients are cared for when they are discharged from the ward but are still awaiting their discharge paperwork, medication from pharmacy, or for transport to be arranged. Staff will explain if the person you care for is to be moved here.

Questions to consider before and during discharge:

- Has the medical condition changed? If so, how?
- Are there changes to the medication? Is this permanent or will it need to be reviewed?
- Has mobility changed? How will using stairs, toilet, bed etc., be managed?
- Is any equipment required for discharge? When will it be delivered?
- Is my caring responsibility likely to increase because of this admission?
- Do I need to arrange a visit for a GP review or a hospital outpatient appointment?
- If a care package or home visit is arranged, when are the first visits? What are the contact details for each?

Transition to Community Care

Transition

When the person you care for is discharged, either you or they will be given a copy of the letter that is sent to your GP surgery. This letter explains to the GP the reason for the admission, treatment, investigations and findings. Any medication changes and follow-up arrangements will also be outlined in this letter.

The person you care for will be sent home with two weeks' supply of medication, if required. The names and explanation of all medicines should be given to you by the nurse or pharmacist on the ward before discharge. Your GP will prescribe any further medication if it needs to be continued. Your local pharmacist is also able to give information and offer assistance if you are having trouble managing the medication regime.

Once home, it is useful to prepare (or update) a list of all medications being taken so that you have the information in one place ready to access in an emergency or to bring to any medical appointment (see page 22, 'Message in a Bottle' scheme).

What to do if the person you care for becomes unwell:

Non-urgent concern:

- If the person you care for becomes unwell, contact your GP surgery for an appointment. If this is out of hours, call **NHS 111** where you can speak to a fully trained adviser. Depending on the situation, the NHS 111 team can connect you to a nurse, a GP or even an emergency dentist. They can arrange face-to-face appointments if they think one is needed
- NHS Choices is an online health library that has information on an extensive range of health conditions, treatments, advice and services near you. The website is **www.nhs.uk/pages/home**
- Your local pharmacist can also advise on minor health concerns, such as coughs, colds, aches and pains, as well as medication, healthy eating and stopping smoking

Urgent concern/life-threatening:

- If you are worried about an urgent medical concern, telephone **NHS 111**. The advisers can assess if an ambulance is required and send one immediately if necessary
- Call **999** for an ambulance if the situation is life-threatening

What if I can't cope?

You may worry how you will cope when the person you care for comes home from hospital. It may be that you have suddenly become a carer as a result of the hospital admission and you are feeling anxious and apprehensive about these changes. These feelings are normal but if you feel you cannot continue to care for the person you support when they are discharged, please let hospital staff know as soon as possible so help can be offered.

If you are at home and feeling overwhelmed, it is important that you speak to someone. Carer support organisations (see page 18) can provide you with practical advice and support to help you in your caring role. Your GP practice is also there to help support you with your general health and wellbeing. If you can, speak with your family and friends and let them know if you are struggling.

It's important that you don't just keep carrying on. It is better to get support early in your caring journey and to look after yourself, as this will enable you to be able to continue caring.

Who can help me if I become unwell?

It is important to look after your own health and not put off any health related appointments. At any health appointment, let the doctor, nurse or therapist know you are a carer. If you have an operation or procedure planned, let the staff know you are a carer at the pre-admission appointment, especially if you have to organise care for the period that you are in hospital.

Having a contingency or backup plan is important. If you unexpectedly become unwell and cannot look after the person you care for, the contingency or backup plan can then be used.

Contingency Planning

Assessment & Support

Involvement

If you look after a child, relative or friend who is ill, frail or disabled, you may worry about what would happen if you were unable to care for them. How would they cope if you were suddenly taken ill, caught in traffic or even in an accident yourself? Who could be called on to help out – even on a temporary basis?

How will having a contingency plan help?

The contingency plan (also known as backup plan) will outline arrangements for cover that could be put in place at short notice if you are unable to provide care. The plan could include:

- The support available from relatives, friends and neighbours
- Formal services that the local authority would need to organise
- A mixture of the two – some formal services to supplement support from family and friends

Any friends or relatives who agree to be part of the plan will need to give written consent for their details to be held. Once this has been arranged and the full plan registered, you will be provided with a **Carers' Card** to carry with you.

It looks something like this:



Your carer support organisation (see page 18) or local authority (see page 19) will be able to advise and assist you to draw up a plan that can be used in an emergency.

What should carers expect?

Caring for someone covers lots of different things, such as helping with washing, dressing, feeding, ensuring medication is being taken correctly, checking to ensure someone is okay, taking someone to regular appointments or being a companion when they are anxious or lonely. The Care Act 2014 legally entitles all adult carers to a **Carer Assessment**. This is regardless of the level of support you are providing someone.

A Carer Assessment is carried out by the local authority where the person you care for lives. You can have a Carer Assessment even if the person you care for does not get any formal help from their local authority. You don't need the permission of the person you care for to request a Carer Assessment, you are entitled to one in your own right.

The purpose of the assessment is to look at the different ways that caring affects your life and to work out how you can carry on doing the things that are important to you and your family; it looks at your physical, mental and emotional wellbeing.

Your assessment should cover:

- Your caring role and how it affects your life and wellbeing
- Your health – physical, mental and emotional issues
- Your feelings and choices about caring
- How your caring role affects your work, study, training and leisure
- Relationships, social activities and your goals
- Housing
- Planning for emergencies, such as a backup plan

The aim of the assessment is to help you get the support that you need, so it's best to give your honest opinion about your caring role, the care you provide and your feelings about being a carer. As a result of an assessment you may be eligible for support from your local authority, who will offer you advice and guidance to help you with your caring responsibilities. You may wish to request a review of your Carer Assessment if your caring responsibilities change.

If you are a parent carer, for information regarding a Carer Assessment, please see page 14.

Caring for someone who does not live near you

If you do not live with or near to the person you care for, or if your circumstances mean it can take a long time to get to their home, it can make caring more difficult. In these situations it is important to plan ahead and consider any potential issues.

Benefits

Understanding benefits that you and your cared for may be entitled to can be a confusing and long process, however, it is worth checking this. Age UK, Citizens Advice or the Money Advice Unit at your local authority can help, and they may also help with completing the application forms on your behalf. For local authority contact details, see page 19.

Caring and working

It can be very challenging if you are trying to combine work with caring. The Work and Families Act 2006 gives carers the right to request flexible working. This can take the form of flexible working arrangements: changing shifts to suit caring commitments; compressed hours (working agreed hours over fewer days or shifts); job shares or working from home.

You are able to make one request for flexible working per year. Although, the company you work for is legally obliged to consider your application, they do not have to agree with your proposals. If you wish to make more than one request in a year, you can still approach your employer to discuss flexible working arrangements. For more information about caring and working, contact Carers UK (see page 18).

Parent Carers

Assessment &
Support

Involvement

Transition

Parent carers care for children or young people under 18 years with a variety of disabilities, health conditions or additional needs. These additional needs are often life-long and the challenges faced change as the child/young person grows and develops. Parent carers are life-long advocates for their children.

If you are a parent carer of a child with special needs under 18 years, or you are a young carer, you have similar rights to a Carer Assessment and support (as with adult carers) but the responsibility is covered by the Children and Families Act 2014.

It is important to note that other children living at home may also help with caring and therefore need some extra support themselves. Having caring responsibilities can have an impact on a young person's schooling, sleep, and friendships. Contact the carer support organisation in your local area for information concerning **Young Carers** (see page 18).

As your child becomes older, if they have complex physical health needs, they can be referred to a **Young People's Health Transitional Service**. The aim of this service is to co-ordinate the transfer of healthcare from paediatric to adult services. This transition starts at age 14 years and may continue up to 21 years of age. If your child has not had a referral to this service, contact their school nurse.

As part of the transition into adult services, it is recommended that you and your child attend your local GP for an annual review from around 14 years of age. The annual health review should include various checks, such as weight, height, blood pressure and a review of diet, bowels and continence. If your child is registered with the GP practice as having special needs, you should automatically be given a double appointment.

When your child reaches 18 years of age, your legal parental responsibility ends. Please discuss what this means for your circumstances with the Young People's Health Transitional Service or your child's school nurse.

As your child transitions into adult healthcare, they will be supported by the **Health Liaison Team** (HLT). The HLT provide expert advice and support to adults with a learning disability in using healthcare services to get the care they need. For more information about this contact your local authority (see page 19). For information concerning your specific needs as a parent carer, contact your local carer support organisation (see page 18) or Parent Network support group (see page 22).

Looking After Yourself

Identification

Assessment &
Support

When you are caring for someone, it is important to look after yourself and stay as healthy as possible. It is easy to forget about your own wellbeing when you are trying to cope with day-to-day events and responding to the needs of the person you care for. It can be difficult to care for someone when you are feeling 'under the weather'. Many carers forget to look after their own health and wellbeing as they put the needs of the person they care for first.

Tell your GP you are a carer

It is important that you register as a carer with your GP surgery. If your GP surgery is aware that you have caring responsibilities, they may be able to offer you more support. For example, appointments can be arranged at more suitable times, you can be offered a free flu vaccination and have your own annual health checks. Speak to your GP practice for more information. Your GP surgery can be an invaluable source of help and advice, and can also put you in touch with other services that can support you and the person you care for.

Have regular check-ups

Although your life is busy juggling caring with your other responsibilities, such as family life and work, don't ignore your own health needs. Try not to miss medical appointments and attend regular check-ups and screenings. If you have not seen your GP for some time, arrange a health check. This will involve checking your blood pressure, weight and urine, as well as a general discussion about your health and how you are coping.

If you are ill, visit your GP

Many carers carry on regardless through coughs, colds, 'flu, stomach upsets and worse. However, it is important that you do not put off seeing your doctor when you need to, especially if you feel faint, dizzy or have unexplained pains and symptoms. The sooner you see your doctor, the more effectively you can be treated.

Moving and handling

Carers may find that they are moving and handling the person they care for more as time goes on. This can include helping them dress and helping them move around. Repeated movements or moving incorrectly can put an extra strain on your back. There may be local courses available to enable you to learn effective and safe moving and handling techniques; contact your local carer support organisation to enquire about these (see page 18).

Ask your GP, district nurse or social care worker to advise you on what aids are available to assist you. These could include:

- Grab rails beside the bed or toilet to help the person pull themselves up
- Mobility aids to help the person you care for move around the house more easily
- Moving and handling equipment to help move the person you care for

Mental wellbeing describes your **mental state** - how you are feeling and how well you can cope with day-to-day life. Our mental wellbeing is **dynamic**. It can change from moment to moment, day to day, month to month or year to year.

If you have good mental wellbeing you are able to:

- Feel relatively confident in yourself and have positive self-esteem
- Feel and express a range of emotions
- Build and maintain good relationships with others
- Feel engaged with the world around you
- Live and work productively
- Cope with the stresses of daily life
- Adapt and manage in times of change and uncertainty

As a carer there may often be times when you feel pressure, stress and even anxiety. When you are focusing on the person you are caring for, it is important to ensure that you do not neglect your own wellbeing.

Most carers need some additional support. Think about whether family and friends could help you. People don't always know what they can do to help but may be happy to lend a hand if you can tell them what you need.

Maintaining your own wellbeing

Remember you are not alone. It can be reassuring to talk to other carers and discover that your feelings are similar to others in your situation. Get help from your friends and family, local carers' groups and speak to your GP. Also, ensure that you watch your stress levels. It is easier said than done, but it is important for you to be able to relax, not being able to do so can affect your health.

Below are some tips that many people say have helped them in creating a sense of their own wellbeing. Some of these may seem obvious but they can often be forgotten during the course of a busy day:

- Learn to say 'no' – you cannot do everything
- Take time out for yourself – do something you enjoy
- Join a support/self-help group. Carers tell us that speaking to other carers is often the best type of support
- Ask your GP surgery to register you as a carer
- Ask for a Carer Assessment
- Talk to someone - this could be a friend, peer or even a local service
- Form a WhatsApp group with family and friends to help share caring responsibilities

End of Life Discussions

Involvement

Transition

It is important to have discussions with the person you care for, and family, about any wishes for future care. Although no single conversation can cover all the decisions that may be faced in the future, such as having a life-limiting illness or the loss of mental capacity, talking about it can make it easier for those who have to make decisions when the time comes.

Having these discussions early can provide a shared understanding of what matters most to the person you care for, you and those close to you. Some of the decisions may concern where you want to be cared for, who you want to care for you, what treatment you have and where you want to die. It means the specific wishes can be known, recorded and respected.

By talking to your healthcare team and/or GP, the person you care for, and you, can consider all the options and make informed decisions about health and wellbeing, which will give you both peace of mind.

When Your Caring Role Changes or Ends

Assessment & Support

Transition

Looking after someone may be a large and significant part of your life, your caring role will change over time, and may come to an end. This may be because the person you are looking after has recovered and no longer needs care, because they can no longer be cared for at home, or because they have died.

If the person you care for were to move to residential or nursing care, your caring role does not necessarily stop, it just changes. Your local carer support organisation will still continue to support your caring role.

When someone close to you dies it can be devastating. If you have been caring for that person, the loss can seem even greater. How you process your feelings about the death of the person you looked after is a very personal thing. Talking about what has happened, and about the person who has died, can help you to work through the feelings you may have. Friends and relatives who also knew the person who died can share memories of them with you and can be a great source of support. Talking to other people who have been bereaved, and who have a good understanding of what you may be going through, can also help. If you need support, contact your local carer support organisation (see page 18), they will be able to advise you about local bereavement organisations.

The end of your caring role may take some time to adjust to. Having more time to yourself may give you the opportunity for a much needed rest. Some people find that once they are no longer caring, exhaustion (both physical and emotional) catches up with them and they may feel unwell for a while. Contacting your GP for physical and mental support is important at this time.

Contact Details

Identification

Assessment &
Support

Transition

Carer Support Organisations

These offer a range of free support to carers, including advice and support to plan your caring role. They can help you look after your own health and wellbeing by providing a range of free courses and activities, and can advise on arranging short breaks from caring. Check below for the carer support organisation local to where you live.

[Action for Family Carers \(supporting carers across Essex\)](#)

Tel: 0300 770 8090

Email: info@carersinessex.org.uk

www.affc.org.uk

[Carers in Bedfordshire](#)

Tel: 0300 111 1919

Email: contact@carersinbeds.org.uk

www.carersinbeds.org.uk

[Carers in Hertfordshire](#)

Tel: 01992 586969 or 01992 586959

Email: contact@carersinherts.org.uk

www.carersinherts.org.uk

[Carers Trust](#)

Tel: 0300 772 9600

Email: info@carers.org

www.carers.org/

[Carers UK](#)

Tel: 020 7378 4999

Email: info@carersuk.org

www.carersuk.org/

[Crossroads Care Hertfordshire North](#)

Covers the towns and villages of North Herts, Stevenage, Welwyn, Hatfield, Dacorum, St Albans, East Herts and Broxbourne.

Tel: 01462 455578

Email: info@crossroadshn.org.uk

www.crossroadshn.org.uk

[Crossroads Care Hertfordshire South \(have joined forces with Carers in Herts\)](#)

Covers the boroughs of Hertsmere, Three Rivers and Watford

Tel: 0208 905 1158

Email: info@cch-south.org

www.carersinherts.org.uk

[Luton Carer Support](#)

Tel: 01582 547659 or 01582 547660

www.luton.gov.uk/Health_and_social_care/adult_social_care

Local Authority Support for Carers

Provide support and advice concerning social workers, personal care, Carer Assessments and more.

Bedford Borough Council

Tel: 01234 267422

Email: care@bedford.gov.uk

www.bedford.gov.uk/health_and_social_care/carers

Central Bedfordshire Council

Tel: 0300 300 8303

Email: customers@centralbedfordshire.gov.uk

www.centralbedfordshire.gov.uk/health-and-social-care/carers/advice

Essex County Council, Social Care Team

Tel: 0845 603 7630

www.essex.gov.uk/Health-Social-Care/Pages/Health-and-Social-Care.aspx

Hertfordshire County Council, Adult Care Services

Tel: 0300 123 4042

www.hertfordshire.gov.uk

Luton Borough Council

Tel: 01582 546000

www.luton.gov.uk

Blue badges (Luton)

Tel: 01582 547272

Email: bluebadges@luton.gov.uk

Other Support Organisations

Age UK

Support vulnerable, older people within the community. They provide a range of services to help you live more independently in your own home, over the phone advice, Lasting Power of Attorney, money and benefits advice and support.

Bedfordshire

Tel: 01234 360510

Email: enquiries@ageukbedfordshire.org.uk

www.ageukbedfordshire.org.uk

Essex

Tel: 01245 346 106

Email: info@ageukessex.org.uk

www.ageuk.org.uk/essex/

Hertfordshire

Tel: 0300 345 3446

Email: info@ageukherts.org.uk

www.ageuk.org.uk/hertfordshire/

Alzheimer's Society

Information and support for people with Alzheimer's and those who care for them.

Tel: 0300 222 1122 (National Dementia Helpline)

www.alzheimers.org.uk

British Lung Foundation - Breathe Easy groups

Providing information, advice and local Breathe Easy support groups for all people affected by lung conditions.

Tel: 03000 030 555

www.blf.org.uk

British Red Cross

Help anyone who may be in a crisis. From hiring wheelchairs and commodes, to first aid courses.

Tel: 0344 871 1111

Email: contactus@redcross.org.uk

www.redcross.org.uk

Carers' Passport Card (Central Bedfordshire and Bedford Borough)

A resource for carers that gives financial savings, services and business offers.

Tel: 0300 111 1919

Email: contact@carersinbeds.org.uk

Carers' Passport Discount Card (Hertfordshire)

A resource for carers that gives financial savings, services and business offers. There are currently almost 400 discounts/concessions available with the Carers' Passport Service.

Tel: 01992 586969 or 01992 586959

Email: contact@carersinherts.org.uk

www.carersinherts.org.uk

Citizens Advice

For free, independent and confidential advice on legal, money and other problems. See their website for your local office.

www.citizensadvice.org.uk

Counselling Directory

Providing information and advice. There are also events, such as workshops, talks and support groups covering a wide range of subjects, from stress and anxiety, to art therapy and general wellbeing.

www.counselling-directory.org.uk

deafPLUS

Promoting independence for those with hearing problems and visually impaired.

Tel: 020 7790 6147

www.deafplus.org/

Dementia UK

Information, advice and support.

Tel: 0800 888 6678

www.dementiauk.org/

Driving Miss Daisy

Provide companion driving services for the elderly, children, disabled people and for anyone who is unable to drive. The dedicated drivers will also help you in and out of the car, going to appointments, shopping and accompany you on outings. Special requirements are catered for, including assistance with a walker or wheelchair. There is a cost associated for this service. Check availability in your area.

Tel: 0333 014 6211

www.drivingmissdaisy.co.uk

Get Meals at Home (Meals on Wheels)

Meals delivered to your home. For more information visit the government website below or contact your local authority for more information (see page 19).

www.gov.uk/meals-home

Headway Hertfordshire

Help people in Hertfordshire who are affected by an acquired brain injury.

Tel: 0300 330 1455

Email: enquiries@headway-herts.org.uk

www.headway-herts.org.uk

Hertfordshire Action on Disability (HAD)

Helping older and disabled people to lead independent lives.

Tel: 01707 324581

www.hadnet.org.uk

Hertfordshire Independent Living Service (HILS)

Provide meals on wheels service for a small cost. They also give medication prompts if required, offer a nutrition and wellbeing service, key safes, home eye testing and many other services.

Tel: 0330 2000 103

Email: info@hertsindependentliving.org

www.hertsindependentliving.org/

HertsHelp

Provides independent support, advice, guidance and information you need on local community and voluntary services, including links to grants and benefits in Hertfordshire. They can also make referrals (if necessary) to community navigators who give extra support to address social needs.

Tel: 0300 123 4044

Text: Text hertshelp to 81025

Email: info@hertshelp.net

www.hertshelp.net

HertsWise

A service designed with people living with dementia, low level memory loss or mild cognitive impairment, and their friends, family and carers in Hertfordshire.

Tel: 0300 123 4044

www.hertswise.org.uk

Macmillan Cancer Support

Cancer support charity providing practical, medical and financial support.

Tel: 0808 808 0000

www.macmillan.org.uk

Mencap

Providing a voice for people with a learning disability. The details below can be used to find regional services.

www.mencap.org.uk

'Message in a Bottle' Scheme

You can get a small bottle and two labels for free. Put vital personal and medical information inside the bottle and keep it in the fridge. Then one label is fixed to the inside of the front door and the other to the door of the fridge. Emergency services will know there is a bottle to pick up by these two labels. You can obtain a bottle from your GP Surgery, local pharmacy or contact:

Lions Club - Tel: 0845 833 9502

Email: enquiries@lionsclubs.co

MS Society

Advice, support and information.

Tel: 0808 800 8000

www.mssociety.org.uk

National Network of Parent Carers

Aims to deliver better outcomes for families living with special educational needs and disabilities (SEND). To find your local network, visit the website.

Email: info@nnpc.org.uk

www.nnpfc.org.uk

Parent Network

Offer parents emotional support, information and education.

Tel: 01442 219720

Email: info@familiesinfofocus.co.uk

www.familiesinfofocus.co.uk

Parkinson's UK

Parkinson's support, advice and research charity.

Tel: 0808 800 0303

www.parkinsons.org.uk

POhWER

A charity that provides information, advocacy and advice services across England. The independent, free services reach individuals struggling with particular challenges in their lives.

Tel: 0300 456 2370

Text: Text **pohwer** with your name and number to 81025

Email: pohwer@pohwer.net

Samaritans

24 hour telephone helpline for people in crisis.

Tel: 116 123

Email: jo@samaritans.org

www.samaritans.org/

Stroke Association

Information and support for those living with and caring for someone who has had a stroke. There are also local support groups.

Tel: 0303 3033 100

Email: helpline@stroke.org.uk

www.stroke.org.uk

Revitalise

Provide short respite breaks for physically disabled people and carers.

Tel: 0303 303 0145

www.revitalise.org.uk

Waterways Experiences

Provide affordable canal boat trips (day and longer trips) for individuals and groups with disabilities and their carers. They operate three large canal boats designed to provide access for the less mobile and accessibility for wheelchairs.

Tel: 01923 723819

www.wexp.org.uk

Working Families

A UK work-life balance charity who help working parents and carers and their employers find a better balance between responsibilities at home and work.

Tel: 0300 012 0312

Email: advice@workingfamilies.org.uk

www.workingfamilies.org.uk

Please note, the support organisations included in this handbook are not an exhaustive list.

Contact Details of Hospital and Community NHS Trusts

East and North Hertfordshire NHS Trust

Lister Hospital
Coreys Mill Lane
Stevenage
Hertfordshire
SG1 4AB

Tel: 01438 314333
www.enherts-tr.nhs.uk

Hertfordshire Community NHS Trust

Unit 1a, Howard Court
14 Tewin Road
Welwyn Garden City
Hertfordshire
AL7 1BW

Tel: 01707 388000
www.hct.nhs.uk

Hertfordshire Partnership University NHS Foundation Trust

The Colonnades
Beaconsfield Road
Hatfield
Hertfordshire
AL10 8YE

Tel: 01707 253800
www.hpft.nhs.uk

The Princess Alexandra Hospital NHS Trust

Hamstel Road
Harlow
Essex
CM20 1QX

Tel: 01279 444 455
www.pah.nhs.uk

West Hertfordshire Hospitals NHS Trust

Watford General Hospital
Vicarage Road
Watford
Hertfordshire
WD18 0HB

Tel: 01923 244 366
www.westhertshospitals.nhs.uk

