

Looking after someone

Northumberland Carer's Guide and Wellbeing Check

Issued by Adult Social Care



Contents

Introduction	2
Key sources of information and support	3
Your health	7
Looking after yourself	9
Caring with confidence	11
Keeping safe	13
Equipment, technology and getting around	15
Juggling work and care	17
Money and legal matters	19
When caring ends	21
What to do next	23
Key contacts	26

Introduction

If you give regular unpaid help and support to a family member or friend who has a disabling condition or long term illness then you are a 'carer'.

You may not see yourself as a carer and many people prefer not to use the term, but recognising your caring role is important in accessing the wide range of information and support that is available. The help you provide could be emotional, physical and/or practical and you may or may not live with the person you care for.

Whether the person has physical or mental health needs, is frail in old age or has problems due to drugs or alcohol misuse, this is likely to impact on your life. Of course, it's natural to put their needs first, but it's really important that you think of your own needs too as whilst caring can be very rewarding, it can also be incredibly stressful and exhausting at times, taking a toll on your own health and wellbeing.

The aim of this guide is to help you identify the right kind of information and support you need to help you to care safely and effectively. It will also help you to think about your own health and wellbeing and identify areas where you may need help.

Key sources of information and support

Carers Northumberland

01670 320 025

Email: info@carersnorthumberland.org.uk

www.carersnorthumberland.org.uk

Carers Northumberland is a charity dedicated to improving the lives of carers.

Support to help you in your caring role may include:

- Information promoting carer rights, (e.g. benefits; assessment; support, employment)
- Emotional and practical support, support groups
- Workshops, training for carers and events
- Small grants to take a break
- Emergency planning and a carers' emergency card
- A voice in local, regional and national developments
- Regular newsletters and e-news bulletins
- Support when your caring role ends

Many other service specific organisations support carers in the county, for example: Escape Family Support (substance misuse), Alzheimer's Society (dementia), Age UK (older people) etc.

Carers Northumberland can signpost to a range of condition specific or specialist services.

Adult Care services

01670 536 400

Email: Socialcare@northumbria.nhs.uk
www.northumberland.gov.uk/adult

Social care support for ill or disabled adults in Northumberland is operated by Northumbria Healthcare NHS Foundation Trust in partnership with Northumberland County Council.

Support to help you in your caring role may include:

- Short term support following an accident or sudden illness
- A carer's assessment or a needs assessment for the person requiring support
- Equipment to help you care safely or telecare information
- Addressing concerns about keeping yourself or others safe from harm or abuse
- Taking a longer break from caring
- Support with end of life care

If the person you are caring for needs care and support which you don't feel able to provide, or if you need support yourself, you should contact adult social care on 01670 536400. We will discuss with you a range of options, including any support that might be useful to you which is available from other services and organisations in the community. Anyone with care and support needs has a right to a "needs assessment" to consider whether they are eligible for services funded by us, and we will offer advice to help them to decide whether this would be useful.

If the person you care for does have a needs assessment, we will involve you in this and we will encourage you to agree to let us also carry out a "carer's assessment" looking at your own needs. Usually we will do this as part of the needs assessment, but if you want you can choose to have your carer's assessment recorded separately. Whichever option you choose, we will give you (and the person you care for) a chance to talk to us privately, in case there are things that either of you finds it hard to say in front of the other person. By assessing your needs as a carer, we can make sure that we take account of these when we plan care and support for the person you care for, and we may also offer you support for yourself.

If the person you care for doesn't want a needs assessment, you can still ask for a carer's assessment. We recommend talking to Carers Northumberland about whether you might benefit from that.

We will tell you more about support and about having a carer's assessment throughout the guide.

NHS services

NHS Choices: www.nhs.uk

All NHS services and practitioners work with and offer support to carers.

Support to help you in your caring role may include:

- Your GP surgery can tell you about health checks, annual flu jabs and screening programmes that are available to carers to help you protect and improve your own health.
- Information about health conditions.
- Specialist advice from a range of therapists/nurses.

Your health

When you care about someone else, it's very easy to forget about your own health. However, it is important to look after yourself so that your health doesn't suffer and you can continue caring for as long as you want to.

Don't avoid talking to your GP about any new symptoms or changes you've noticed and don't always put the way you are feeling down to simply being a carer, for example if you are more tired than usual there may be some treatable cause.

Many people, not just carers, have times when they feel low or sad and can't find any pleasure in life. When these feelings last for weeks or months rather than a few days it may indicate depression, a common health issue associated with caring. Depression is an illness; it is not a sign of weakness or something you can 'snap out of'. If you think you may be suffering from depression you should see your GP as soon as possible. The treatment and support options for depression are very effective and the sooner you get help the sooner you will feel better.

Another common health issue can be back and neck injury. Make sure you have the right equipment to help you in your caring role and that you are confident in using it. Always seek advice and avoid heavy manual lifting.

Be nice to yourself; don't get so caught up worrying about the person you care about that you end up neglecting your own health.

Finding time to take care of your own health and wellbeing will help you re-energise and help you cope with the pressures caring can sometimes bring.

Check your wellbeing

- Is there anything about your physical health that worries you?
- Have you been offered any type of health check or screening in the last year but not taken up the offer?
- Have you had a fall or any problems with your balance in the last year?
- Do you experience any pain associated with moving or handling the person you care for, or using any equipment?
- During the last few months have you often felt down, depressed or hopeless?
- Do you worry about your memory getting worse?

Have you experienced any of the following?

- Increased thirst
- Increased passing of urine or blood in your urine
- Changes in your bowel habits, or blood in your stools
- Changes in your breasts / chest (this also applies to men)
- Chest pain
- Breathlessness
- More tired than usual

Where to get help

If you answer “yes” to any of the questions above you should call your **GP surgery** to make an appointment, if you haven't already done so. Prevention and early intervention is always the best option and in most instances a GP consultation will give you peace of mind and one less thing to worry about.

Looking after yourself

Caring can place huge demands on your time and energy and for many carers stress is simply a fact of life. However, carers can also feel very positive about caring.

If you feel overwhelmed this can often lead to stress, anxiety and depression which in turn can make caring more difficult. It is not unusual for carers at times to have feelings of anger, grief, loss, or of feeling trapped. You should not feel guilty if you have these feelings, they are normal.

You may think that talking doesn't solve things, but many carers find that having someone to talk to is one of the most important kinds of help they have. Joining a carers group could offer you the opportunity to share your experiences with other carers or give Carers Trust and Carers UK online forums a try.

Taking a break from the demands of caring is important, this may mean taking time out for yourself at some point in the day to having a longer break to recharge your batteries. You may be able to make informal arrangements with family or friends to stay with the person while you have a short break. Many people do want to help but don't know how, it will help if you are specific about the help needed and how long it will take.

If you feel the demands on you are such that you need formal help to take a break then a carer's assessment will help you to think about the times when a break would be most useful and ways of making caring easier, often by increasing support for the person you care about, to allow you a break.

Eating healthily or getting any form of exercise may be the last thing on your mind, but a healthy lifestyle will help reduce stress levels and improve sleep. Including fresh fruit and vegetables in

your diet will help. Exercise doesn't have to be vigorous to be worthwhile and you may be able to do it alongside caring.

Check your wellbeing

- Do you sometimes feel overwhelmed?
- Would you like help or information about meeting other carers for mutual support?
- Do you have the opportunity to take time away from caring, to do the things you enjoy?
- Does caring leave you with enough time and energy to get to the shops and other places where you need to go, and to take part in leisure activities that matter to you?
- Does caring affect your relationships with other family members or friends?

Where to get help

Carers Northumberland can tell you about carer groups or link you with other carers and support to help you take a break. Call 01670 320 025 or email info@carersnorthumberland.org.uk.

If you feel you need help to take a break contact **adult care** on 01670 536 400 or email socialcare@northumbria.nhs.uk for a carer's assessment and support.

If you have problems with other health issues, for example diet, smoking, getting exercise, then a health trainer can help you look at ways to live a healthier lifestyle alongside caring. Ask at your surgery or email the **health improvement team** for advice healthtrainers@northumbria.nhs.uk

Caring with confidence

No one is born knowing how to be a carer. Most people learn how to look after someone by trial and error and by relying on their own knowledge.

Thinking about the physical and emotional demands caring places upon your life will help you identify the type of support that would help you most to continue caring, or talk about ways to reduce your caring responsibilities.

Be informed, find out everything you can about the health problems affecting the person you care about, for example, their treatment, what to expect, medication and side effects. Consent from the person you care about will be needed for some information sharing, but there is also a range of good quality general information and tips on the internet. It will make a big difference to you if you understand what's involved. The NHS Choices website is a good place to start as it provides information on lots of conditions.

Advice and training is available from many of the services and organisations that you may come into contact with. Health and social care practitioners can help you to access specialist information, for example practical advice on things like safe moving and handling, dealing with aggression/mood swings, relaxation techniques and helping with treatment and therapy.

If you feel unable to continue with the demands caring places on you, it may be time to talk about additional help or alternatives that are available to the person you care about, to allow you to reduce or stop your caring responsibilities. If you have concerns about any aspect of your caring role or you would like more help with certain tasks ask for a carer's assessment or review of your situation.

Check your wellbeing

- Is there anything about the illness or condition of the person you care about that you don't fully understand or need help with, (e.g. symptoms, behaviour, treatment or medication)?
- Are there any caring tasks that you would prefer not to do or that cause you difficulty?
- Are there any caring tasks that you would like help to develop more skills or confidence in, (e.g. first aid, giving medication, moving and handling)?
- Do you find the behaviour of the person you care about upsetting at times?

Where to get help

NHS Choices is a good place to start for information and advice on NHS services, healthy living and health conditions www.nhs.uk or ask at your GP surgery.

Carers Northumberland run *Caring with Confidence* courses, which look at dealing with both the physical and emotional demands of caring, also offering an opportunity to talk to other carers and to share tips and coping strategies.

01670 320 025 or visit www.carersnorthumberland.org.uk

For a carer's assessment or needs assessment speak to your social worker or care manager (if you have one), call **adult care** 01670 536 400 or email socialcare@northumbria.nhs.uk

Keeping safe

Carers are in the best position to protect the person they care about and raise concerns if they feel they are being abused or neglected by others. If you or the person you support are being victimised by others due to your situation, don't keep it to yourself – tell someone!

Caring for someone can be very isolating and sometimes carers may be at risk of harm by the person they care about, often due to the symptoms of the person's illness, but for other reasons too. Equally, caring for someone can also be extremely stressful and stretch the most placid people to the limits of their patience. If you find yourself in such a situation it is important that you are able to share these feelings with someone, so that you can get the support you need before things become too much.

There are a variety of other ways in which safety and wellbeing can be threatened or undermined. Protecting against scams, for example by email, fake websites, over the phone or face to face (including bogus callers), is an important part of keeping safe. There are lots of ways you can protect yourself and the person you care about against scams and fraud. Citizens Advice, Trading Standards and other consumer organisations provide information about how to do this.

Having a carers emergency card will give you peace of mind should something unexpected happen to prevent you being with the person you care about. By deciding in advance what you and the person you care about would like to happen, you can ensure a speedy response if you're taken ill, the car breaks down or something else gets in the way of you being there when you need to be. Temporary support can be put in place until longer term arrangements are possible. Carers Northumberland works with the British Red Cross to offer this free service.

Check your wellbeing

- Do you have concerns about the way the person you care about is treated by any other individual they rely on for support?
- Do you ever feel unsafe due to the condition or behaviour of the person you support?
- Do you worry about losing your patience with the person you support?
- Do you ever feel unsafe in your caring role? (e.g. by nuisance phone calls, doorstep traders, loan sharks, anti-social neighbours etc.)
- Do you worry about what would happen if you took ill or in the event of an emergency?

Where to get help

In an emergency or in immediate danger call 999 first.

To report an abusive incident or concern call **adult care** 01670 536 400 or email socialcare@northumbria.nhs.uk

Carers Northumberland can support you and help you decide next steps to take. They can arrange a carers emergency card. 01670 320 025 or email info@carersnorthumberland.org.uk

Citizens Advice offer help in managing nuisance calls and scams www.citizensadvice.org.uk/consumer/

Equipment, technology and getting around

Equipment can make everyday tasks a bit easier and safer. Many useful items are relatively low cost such as tap turners, talking watches or grab rails and are available to buy from chemists or large department stores, online or from some voluntary agencies.

If you think you may need more complicated equipment or adaptations to the home, you can get expert advice from an occupational therapist (OT). You must do this if you want help with the costs but an OT can offer advice even if you will be paying yourself. For example, the person you care for may be struggling with access to their house, bathing or climbing stairs, or need major adaptations to the home. Equipment can be hired privately like stair lifts, wheelchair ramp etc., or they may be eligible for partial or full financial help through the Disabled Facilities Grant from the County Council, based on assessed needs. To estimate grant eligibility the OT will ask the Home Improvement Service to carry out the financial assessment.

Telecare is support provided at a distance using information and communication technology to help people continue to live at home. It may involve community alarms or more sophisticated sensors in the home. Telecare solutions are available from a number of providers, (search online), including Northumberland Telecare, a Northumberland County Council service, (weekly charges apply).

Having access to the internet can bring real benefits. Going online can be useful for practical things like research, shopping or banking as well as getting connected with others through forums or social media. It's also a good way to relax, such as streaming audio books, films or just simply playing a game.

A Blue Badge or Radar Key is worth considering if you or the person you care for have problems getting around out and about.

Check your wellbeing

- Do you need help with managing home repairs, safety and security?
- Do you feel you need advice or assistance in adapting the home to make life easier due to disability?
- Do you worry about leaving the person you care for when you go out or perhaps when you are out together?

Where to get help

For information about **Northumberland Telecare** or to ask for advice from an occupational therapist, call **adult care** 01670 536 400 or email socialcare@northumbria.nhs.uk

Northumberland fire and rescue service offer a free safety and wellbeing check to residents who are over 65 years old or disabled. Call freephone 0800 731 1351 or email NFRSHFSCReferral@northumberland.gov.uk

Apply for a **Blue Badge** or companion pass to travel free when accompanying a disabled person on public transport from Northumberland County Council on 0345 600 6400
For more information see: www.direct.gov.uk/BlueBadgeMap

RADAR keys are available to help people access disabled public toilets across the UK. These cost £5. Contact the RADAR Key Company at www.radarkeys.org or call 01395 222 588 to order.

Juggling work and care

You may feel as though you are juggling two jobs when holding down a paid job and caring for someone, but work can be important for your wellbeing, income and for maintaining social contacts.

If the caring responsibilities are getting you down and you feel unable to cope with both work and caring, talk to your family and the person you support about the problems. Are there any changes you can make that will make your life easier? Accept offers of help and encourage the person you care for to have a needs assessment and to accept outside help; it will also help for you to have a carer's assessment at the same time. Make sure you are clear about what you can and cannot do in order to continue working, if that is what you want.

Think carefully before giving up work to care. Your work will provide you with financial security, time away and a sense of identity which is separate from your role as a carer.

Think about talking to your employer. There may be support that you are not aware of, or you may find your employer is open to exploring new ways to support you. Many employers operate flexible working schemes and many more would do so on an individual basis, but first they need to know that you're struggling. It is always helpful to have thought through any potential changes to your work pattern that would benefit both you and your employer, so if you have an idea, tell your employer about it.

All employees have the right to take a reasonable amount of unpaid time off to deal with emergencies involving someone who depends on them and to make necessary arrangements.

Always seek advice before giving up work to care.

Check your wellbeing

- Do you feel you are struggling to balance your work and caring responsibilities?
- Is your job at risk because of the level of caring that you are providing?
- Do you need information about your employment rights as a carer?
- Is your caring role preventing you from accessing education or training opportunities?
- Have you checked with your HR department or union whether your employer has carer friendly policies?

Where to get help

Carers Northumberland can offer support and advice to working carers and to carers who would like to return to work.

01670 320 025 or email info@carersnorthumberland.org.uk

If you have difficulty juggling work with caring ask for a carer's assessment or review of your situation. Contact your social worker or care manager, or call **adult care**

01670 536 400 or email socialcare@northumbria.nhs.uk

Money and legal issues

Many carers do not claim the benefits and tax credits that they are entitled to. Carer's Allowance is the main benefit that is available to carers, as long as you meet the eligibility criteria. You may be able to claim Carer's Allowance if you spend at least 35 hours a week caring. The person you care for must receive one of the following:

- Personal Independence Payment, (PIP), daily living component at any rate
- Disability Living Allowance, (DLA), care component at the middle or higher rate
- Attendance Allowance, (AA)

Carer's Allowance is paid directly to you, (the carer), but the amount you get may be affected by your other benefits or the amount you earn. Claiming Carer's Allowance can also help you get extra money if you claim other benefits or pension credit.

Legal matters

The Mental Capacity Act, (2005), is a process used when someone lacks capacity to make decisions. It covers anyone over the age of 16 and sets out who can make decisions in which situations and how they should go about it. For more information you can search online "*A guide for family, friends and other unpaid carers*" or ask Carers Northumberland for a copy.

Lasting Power of Attorney, (LPA), is a legal tool that allows a person to appoint someone to make certain decisions on their behalf if there comes a time when the person cannot make decisions for themselves. There are two types that you can arrange – a property and affairs LPA or health and welfare LPA.

You can apply yourself to make a LPA as the forms are easy to complete and available on the Office of the Public Guardian web pages. However, as it is a powerful and important legal document so it may be a good idea to seek advice from a solicitor, especially if your affairs are complicated.

Appointee for benefits: You can apply for the right to deal with the benefits of someone who cannot manage their own affairs because they are mentally incapable or severely disabled. As an appointee you are responsible for making and maintaining any claims and spending the benefit, (which is paid directly to you), in the claimant's best interests.

Check your wellbeing

- Do you know if the person you care about is getting their entitlement to benefits?
- Are you claiming Carer's Allowance?
- Do you want to plan for the future for yourself or the person you care for?

Where to get help

Carers UK 'Upfront guide to caring' is a simple tool for carers who are new to the maze of benefits and entitlements.

www.carersuk.org/upfront

'Turn 2 Us' is a free and easy-to-use benefits calculator and grants search tool. It can help you check what you might be able to claim or apply for www.turn2us.org.uk/Find-Benefits-Grants

Citizens Advice Northumberland provides free advice on a range of issues including debt, energy advice and family law. 03444 111 444 or www.citizensadvice.org.uk/northumberland

When caring ends

Looking after someone is a huge part of your life and it is inevitable that your caring role will change over time. Caring may come to an end when the person you're looking after moves into a care home, or when they pass away.

Many carers find it difficult to adjust when looking after the person at home is no longer possible. This is not inevitable and most people, with help, remain at home. However, if you're becoming exhausted or if the person you care about is getting worse and can no longer live safely in their own home, even with further support for you or for them, then residential or nursing care is a sensible option to consider. Remember, you are only human and there are limits to the care you can provide at home.

This is always a difficult decision and it is not uncommon for carers to feel they are letting the person they look after down. You may still wish to be involved in some elements of the person's care and care homes welcome the involvement of family and friends.

Paying for care is a complex issue and you can get general advice from Age UK. If we assess that you are eligible for services, we will give you information sheets explaining how charges are calculated (also available on the County Council website at www.northumberland.gov.uk/careandsupport), and you will have an opportunity to discuss in detail with a Financial Assessment and Benefits Officer how the charging rules would apply in your financial circumstances.

It may be that your caring role is coming to an end because the person you care about is at the end of their life. Many people want to die at home. Whatever the situation, it is important to realise that you are not alone. The community hospices in Northumberland

help to support families through end of life care as do our palliative care services, including information to help families appreciate what to expect and making plans for caring for a loved one at home.

When someone you love passes away, rebuilding your life can be hard. Everyone's reaction to losing someone is different and there is no right or wrong way to deal with your own grief. Listen to yourself. Do what feels comfortable and helpful for you.

Check your wellbeing

- Do you feel you need more information about care options?
- Do you worry about what might happen to the person you care about in the future?
- Do you need support in adjusting to recent change?

Where to get help

For information about residential care options contact adult care 01670 536 400 email socialcare@northumbria.nhs.uk or visit www.northumberland.gov.uk/careandsupport

Carers Northumberland can offer information and support through this difficult time and beyond and can also help you access **Carers UK** information about managing practical matters 01670 320 025 or email info@carersnorthumberland.org.uk

If you feel you are not coping bereavement support is available, talk to your **GP** who will put you in touch with local support.

Macmillan support service has information about all aspects of living with cancer, any life limiting illness or bereavement. 01670 855 533 or email macmill.support@northumbria.nhs.uk

What to do next

Use the key contacts we have given you to ask for help or to find out about any specific or further information you need.

This guide and wellbeing check is not a carer's assessment; however, it may have helped you decide that a formal carer's assessment would be helpful. It will certainly have helped you to think about the things that concern you the most and to consider the changes you might make or the kind of help or support you feel would benefit you.

Having an assessment of your needs

The carer's assessment involves discussing your situation with a care manager or social worker to help you work out how you can carry on doing the things that are important to you and your family, as well as meeting your responsibilities as a carer and looking after your own wellbeing. The discussion will include:

- Any risk that caring could harm your own mental or physical health.
- Any issues you may have about combining caring with looking after children or other adults who need help.
- Any practical issues about looking after your own home or to eating healthily.
- Any difficulty you may have combining caring with work, education or training.
- Whether caring leaves you with enough time and energy to get to places you need to go, and to take part in leisure activities that matter to you.

You may also want to talk about other ways in which caring is affecting your life.

What are carers entitled to?

You are entitled to support if you have difficulties in any of the areas of life you are asked about that are having a significant impact on your wellbeing.

Often the most important way to make life easier for you will be to adjust the care and support arrangements for the person you care about. This might mean providing some extra support so that you have time during the day to get some rest or do other things; or it may just mean arranging the person's services in a way that doesn't create difficulties for you.

If you are providing a lot of support, or if there are other things going on in your life which mean that you won't be able to provide care during some periods of time, you may need some longer breaks from caring and replacement care may be arranged.

Some carers find that caring leaves them with so little time that they need support with other basic tasks in their lives to enable them to carry on. If caring is taking over your life to the extent that you don't have time to deal with your own basic needs then you will be able to discuss how sustainable this is and the support options available.

Personal budgets and direct payments

Flexibility is often very important for carers. Some carers may find it particularly beneficial to take direct control of any funding for support with their needs.

If you have been assessed as needing publicly funded support, you will be told the estimated cost and whether you will have to contribute. The same will happen if it is agreed that care and support for the person you care about will be funded. If you decide that you want to control some or all of the money yourselves, the care manager will help you to make the necessary arrangements, and will agree with you a final figure for how much money you will need. This is called a 'direct payment'.

Even if you choose to ask adult care to arrange services for you, you will be told how much these are costing – this is known as a ‘personal budget’.

You can, if you choose, summarise your caring role and the things you would like to discuss using the format below. It will act as a prompt for you and make sure you don’t forget things that are important to you when asking for help.

How my caring role affects my life....	My life as a carer would be better if....

Key Contacts

Adult care services	01670 536 400
Urgent out of hours	0345 600 5252
www.northumberland.gov.uk/sds	
Age UK	01670 784 800
www.ageuk.org.uk/northumberland	
Alzheimer's Society Helpline	0300 222 1122
www.alzheimers.org.uk	
Carers Direct	0300 123 1053
www.nhs.uk/carersdirect	
Carers Northumberland	01670 320 025
www.carersnorthumberland.org.uk	
Children's Services	01670 536 400
www.northumberland.gov.uk	
Citizen Advice	03444 111 444
www.citizensadvice.org.uk/northumberland	
Escape Family Support (drugs/alcohol)	07702 833 944
www.escapefamilysupport.co.uk	
Stroke information and support service	0191 293 4326
strokeinfo@nhct.nhs.uk	
Tyneside and Northumberland Mind	0191 477 4545
www.tynesidemind.org.uk	
VoiCeS Northumberland	01665 713 109
www.voices-northumberland.org.uk/youngcarers	

Alternative Formats

If you would like a copy of this information in large print, another language, audio tape or other format please call the Contact Centre on **03 44 811 8118**

Other sources of information

NHS 111

NHS Choices

www.nhs.uk/pages/homepage.aspx

NICE (National Institute for Health and Clinical Excellence)

www.nice.org.uk

Patient Advice and Liaison Service (PALS)

Freephone: **0800 032 0202**

Text: **01670 511098**

Email: northoftynepals@nhct.nhs.uk

Northumbria Healthcare NHS Foundation Trust

General Enquiries **03 44 811 8111**

www.northumbria.nhs.uk

PIN 733/V1

Review date: July 2020

© This material is the copyright of the Northumbria Healthcare NHS Foundation Trust