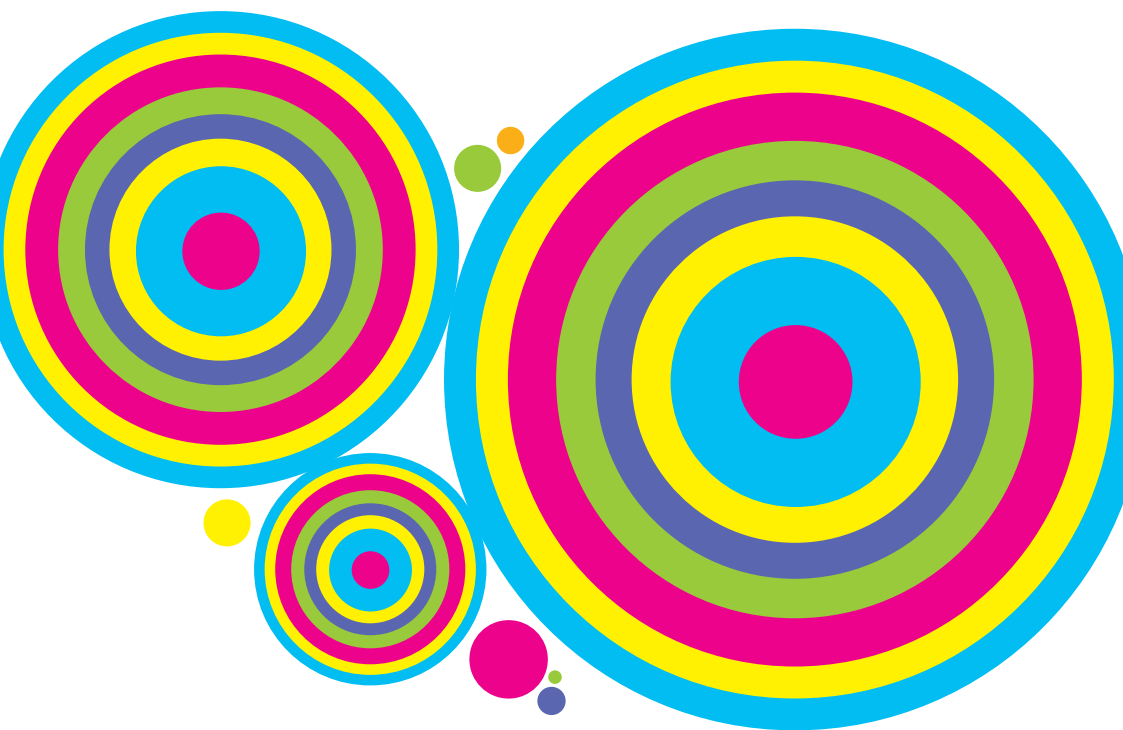


A Guide for Carers



If you look after a partner, relative or friend who has an illness, disability or is elderly and could not manage without your help, then you are a Carer.

You might have never thought of yourself in this way before. We firmly believe that all carers deserve help and support.

This booklet, which sits alongside our carers training videos available on YouTube (look for our channel, Support for Carers Leicestershire) is designed as an overview of what you might experience during your caring journey, as well as a guide to both the practical and the emotional aspects of caring. From benefits to wills, arranging respite care to dealing with feelings of guilt and resentment, this comprehensive guide will be a useful resource for you.

Although much of the information given will be applicable nationwide, this booklet was designed for carers who are looking after an adult 18+ living in Leicestershire, and all phone numbers and information given relate to Leicestershire county residents.

Here at Support for Carers Leicestershire we have a dedicated telephone advice and support line for carers, **01858 468543**.

Please do not hesitate to give us a ring with any queries related to your caring role and let our experienced, friendly staff point you in the right direction.



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Looking after yourself

Look after your own physical health - however busy you are. Even a ten-minute walk will refresh you physically and mentally and help you sleep better.

If the physical side of caring is taking its toll - for example you're getting a bad back from trying to help the person out of bed - social services can arrange a visit by an Occupational Therapist to see if there are any aids or adaptations that might help.

Try to get enough sleep. If you're having disturbed nights because the person you care for wakes you up in the night, could you take a nap in the afternoon? It doesn't really matter when you sleep.

Make an effort to eat well. If you no longer have time to cook from scratch, or perhaps you're new to doing the cooking, there are various food delivery services offering nutritious frozen meals at reasonable prices. You can also get a two-course hot lunch delivered at a reasonable price - see page 11.

Seek some emotional support, whether that's from friends, family or carer support services like ourselves. Some people find it easier to talk to someone who is outside of the situation. You can phone us "as and when" to get things off your chest. We also offer monthly carers support groups where you can meet other carers in similar situations to you.

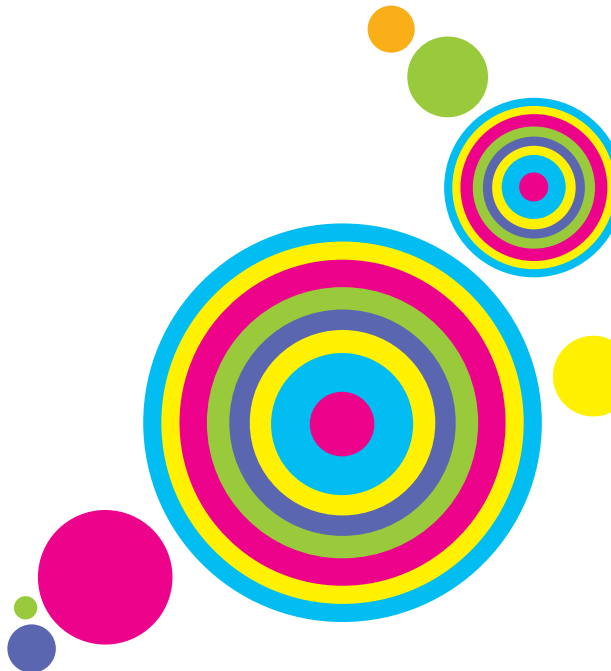


Build small breaks into the day to give you a chance to regain your composure. What you do in those breaks is up to you, the important thing is having them!

- Do something you enjoy doing whether that's reading a book or watching a favourite TV programme
- Guided meditations, breathing and relaxation techniques can really help. There are lots of smartphone apps to help you learn
- Go for a walk, even a walk around the garden can help
- Ring a friend for a chat
- A crossword, word search or sudoku
- A cup of coffee with a friend or neighbour

Consider outsourcing some of your jobs. There is only so much of you to go around. Would having a cleaner once a week be beneficial, or someone to mow the lawn? Do you have friends, family or neighbours who offer to help for example, collecting a prescription or helping with the garden? Let them help you. We are all too good at saying - "No, I can manage."

If you're feeling low; tearful; waking early; lack of appetite, not enjoying things you once did - see your GP for help sooner rather than later.



Dealing with Guilt and Resentment

Guilt and resentment are very common feelings among carers. We speak to carers who are running themselves into the ground for the person they care for, but still don't feel as if they are doing enough. Other carers feel guilty that their caring role affects others in their lives, for example, not spending so much time with their grandchildren. Some carers may feel resentful and bitter that the future they imagined has been taken away from them.

Just as nobody chooses to get ill, you almost certainly didn't choose to become a carer. Don't feel guilty for taking time out from the caring role to protect your own health and happiness. If you burn yourself out, you'll be no good to the person you care for. Practically speaking you can only care for someone well if you are in good health yourself, that includes not being overwhelmed by feelings of stress or guilt.

Unfortunately, it is not uncommon for other family members to be less than supportive to the person doing the majority of the care. Adult children may only visit occasionally, and not fully realise the difficulties being faced on a day-to-day basis. Siblings may be only too happy to let one person take the strain for Mum and Dad. This can feel very unfair.

Often the cared-for person does not seem to know or appreciate what you are doing for them. This can make you feel very resentful, a sense of "Why am I bothering?". Illness can make people insular; only aware of their own needs and problems. Frequently, people with dementia or mental illness have no insight into their condition and think they are perfectly fine, so they won't appreciate all the extra support you are providing.

Be reassured that feelings of guilt and resentment are perfectly normal. If you want to talk it through with someone who won't judge you, give us a ring. We talk to carers on a daily basis and we understand how difficult it can be.



"Mum moved in with us 3 years ago, just as we both retired. She and my wife have never got on very well and they argue all the time - I feel like a referee. We were looking forward to our retirement but we can't do any of the things we'd planned."

"I care for Mum but still go out to work. I don't have a social life any more because I feel guilty leaving her when she's already been on her own all day. I'm only 40 but I feel like I just work and care."

"I would dearly love to go on holiday with my daughter, but it would mean my husband going into respite care for a week. He gets distressed when I suggest it."

"My wife has dementia, and asks me the same things over and over again. I try to be patient but sometimes I end up snapping at her, then she looks so hurt."

"Since my husband first got poorly my own health has deteriorated and I am struggling to look after him. I am thinking about putting him into residential care but our kids went mad. They only visit us once a fortnight though, they don't see how hard it is for me day to day."

**STOP.
YOU ARE ONLY HUMAN.
YOU ARE DOING YOUR BEST.
YOUR NEEDS MATTER TOO.**

Getting the best out of your GP health appointments

We always advise people to make sure their GP practice knows they are a carer. Please fill in a form at your GP surgery to register as a carer. GPs vary as to how much support they offer carers, but at the very least it will ensure you are eligible for a free flu jab.

- Some GPs offer more flexible appointment times for carers.
- Some GPs offer an annual health check with a nurse.
- If you speak to your GP about a condition that could be related to the caring, e.g. you can't sleep for worrying or you've got a bad back from heavy lifting, your GP will know you're a carer and will consider whether that could be a factor.

Many GPs now offer appointments you can book online, or online requesting of repeat prescriptions, which could make your life easier by saving you a trip to the surgery.

To make it easier to manage somebody else's medication, you can request your pharmacy to make up a dosset box which tells you exactly what to take/give on the right day at the right time. This is usually done as a blister pack.



Carer's Assessments

If you look after someone who lives in Leicestershire and you're both over 18, you may be entitled to some support with your caring role through a Carer's Assessment. A Carer's Assessment will look at your existing support network, for example family or friends. It considers the things that you want or need to achieve outside of your caring role and the impact this has on your ability to carry out those activities and how this affects your wellbeing.

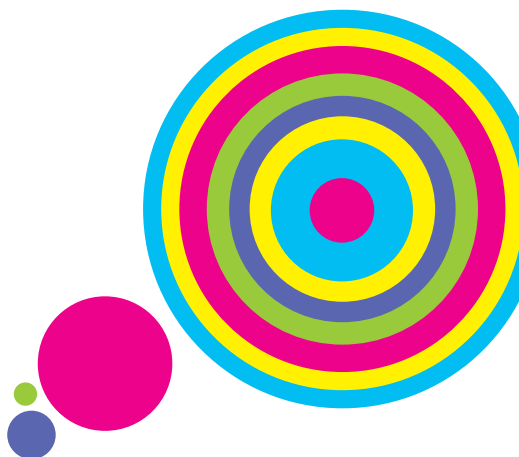
It's not about judging your ability or the way in which you carry out your caring role. Its purpose is to help you to continue in your caring role if you would like to do so.

As a result of your Carers Assessment you'll be offered information and advice, signposting and support you can access locally where appropriate. You may also be eligible for financial assistance, which isn't means-tested.

A Carers Assessment is completed online. You can either do it yourself by going to:

www.leicestershire.gov.uk/adult-social-care-and-health/looking-after-someone/what-is-a-carers-assessment

Or phone us and we will complete it over the phone with you. Either way, it takes about 20 minutes to complete.



Arranging domiciliary care (home care)

If you are at the stage where you feel it would be helpful to have more support, with the person you care for at home, you could consider a care package.

Going through Adult Social Care

- To get the ball rolling, call the Customer Services Centre on **0116 3050004** to request a Community Care Needs Assessment of the person you care for.
- The council will contact you to assess exactly what sort of care package is needed.
- The carers will do basic care tasks like getting the person up or putting them to bed, giving medication, washing, dressing, shaving etc, and sometimes preparing simple meals. Social Services can't help with domestic tasks like cleaning or laundry.

If you go through Adult Social Care the council will complete a financial assessment to decide whether the person should pay towards their care package. They might have to pay for all their care, some or none. The cared-for person then has the choice of having the council arrange their care package, or receiving a Personal Budget to buy in care services of their choice. This could include employing a personal assistant.

In that case they will give you a direct payment card to pay the carers, which is topped up every 4 weeks. Having a personal budget is more flexible but some people prefer not to have the hassle. It's whatever works for you and the person you care for.



Private care agencies

- Tend to be more flexible. You can choose when you want the carers how frequently and how long for, and to a certain extent what they do when they're in your home.
- It's more expensive and there will be premiums for night-time or bank holidays.
- It's worth asking around your friends and neighbours to see who has a good reputation in your area. You could also try CHS Healthcare an award-winning organisation that matches people with the right home care or residential care. They will not charge you for their advice. Their phone number is **0800 008 7193**.

Other options to consider

Sitting services

If you don't like to leave the person you care for by themselves, would a friend or family member offer to sit with them? If not, you can buy in a sitting service from a care agency or certain organisations e.g. Age UK so you can go out and do whatever you need or want to do without worrying about them alone at home. Depending on your circumstances, you may be eligible for a financial contribution towards a sitting service through your Carers Assessment.

Meal delivery services

You probably already know there are various companies who will deliver frozen meals to a person's home. There are also companies that will deliver a 2-course hot meal at lunchtime. They could offer a basic welfare check at the same time, to check that everything is alright. Some companies will, for an extra charge, also leave a sandwich and a piece of cake for tea. Dietary restrictions and special diets can all be catered for. We made a video and a table comparing meal delivery services in Leicestershire which is available online - <https://bit.ly/2UKoscZ>

Respite care

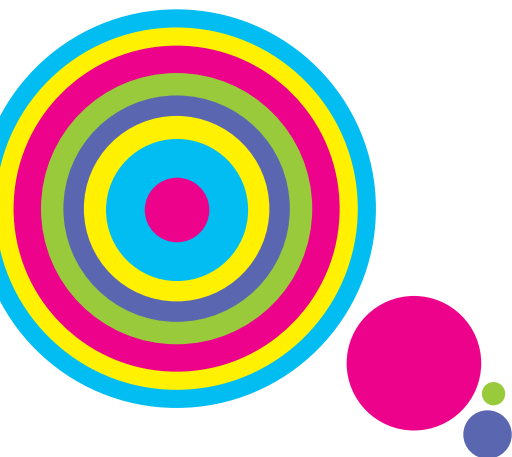
If you need a complete break from caring and there's nobody else willing or able to step into your shoes, you could consider arranging for the person you care for to go into residential or nursing care for a week or longer. The cared-for person has to agree to go into respite, unless they have lost mental capacity in which case different rules apply.

Be aware that not all care homes offer respite care, and often you cannot book more than a few weeks ahead.

If you think you might be eligible for funded respite through **Adult Social Care**, you can phone them on **0116 3050004** for assistance. If you will be paying for the respite yourselves, you can either phone round different care homes and find out if they offer respite care, or contact **CHS Healthcare** on **0800 008 7193** who will help you find a suitable place.

Emergency Respite Care

Hopefully it will never come to this – but sometimes carers end up at breaking point or in crisis, due to extreme carer strain. In these circumstances you may have to request Emergency Respite Care by contacting **Adult Social Care**. The phone number is **0116 3050004**, or **0116 2551606** out-of-hours.




Carers Emergency Plan

It's worth considering what would happen if you fell ill or had an accident and were unable to provide care. Would the person who ends up looking after the person you care for know what to do?

Here at Support for Carers we can send you our Carers Emergency Plan which has space to record details of medication, daily routines, likes and dislikes etc, as well as emergency phone numbers such as your GP, relatives and friends. The idea is that you complete this Plan and keep it somewhere it will be seen. Make sure family and friends know about it and where it is, so if someone had to take over in an emergency they would know what to do.

We can also send you a carers card to go in your purse or wallet which will alert the emergency services to the fact that you are a carer and there is someone who will need to be looked after. It gives your name, the name of the person you are caring for, and who to contact in an emergency.

A card with a rainbow border at the top. The text reads: "I AM A CARER SOMEONE RELIES ON ME" in blue. Below this, there are two lines for text: "My name" and "I care for". At the bottom, it says "Please turn over for my keyholders and emergency contacts" in red.

I AM A CARER SOMEONE RELIES ON ME

My name

I care for

Please turn over for my keyholders and emergency contacts

Message in a Bottle

This national scheme, run by Lions Clubs across the UK, consists of a green and white plastic pot that sits in your fridge. Inside the pot is a form where you can list someone's medical history; current medication; allergies; emergency contacts etc.

There are also two stickers - one for your front door or main entrance, one for your fridge. The emergency services are trained to look out for this as it provides vital information. Message in a Bottle kits are available from various places including libraries and police stations.



Disability Benefits for the person you care for

There are two main benefits to help people with long term illness or disability cover the additional expenses they incur. What you can apply for depends on your age. Neither is means-tested.

If working age - Personal Independence Payment

- You'll be assessed for your Daily Living needs and your Mobility needs.
- You can apply online or download a paper form.
- Most applicants will be called in for a face-to-face assessment.
- The rate will be regularly reviewed to ensure you are being paid correctly.

If pensionable age - Attendance Allowance.

- You can apply online or download a paper form (help is available in completing the form). We advise getting support with completing from a professional, who will help you capture every aspect of your care needs.
- Paid at a higher or lower rate depending on whether the person has care needs at night.
- You have to have had the condition for 6 months or more, unless it's terminal.
- The application can be fast-tracked if the person is terminally ill and not expected to survive longer than 6 months. In this case, it doesn't matter how long they have had the condition.

Some people may still be receiving Disability Living Allowance, but PIP is gradually replacing this.

If there are any hospital admissions keep the department of Work and Pensions informed on:

PIP - 0800 1214433

Attendance Allowance - 0800 7310122

Benefits for Carers

Carers Allowance

Carers Allowance is designed to replace some of your earnings if you can't work because of your caring role.

The person you care for must be on a qualifying benefit, either - Personal Independence Payment or Daily Living Component; Disability Living Allowance - the middle or highest care rate; Attendance Allowance; Various legacy benefits - phone the Carers Allowance Unit on **0800 731 0297** for advice.

- You must be caring for the person 35+ hours a week.
- You can still earn a small wage while claiming Carers Allowance check online for the current limit.
- You can only claim one lot of Carers Allowance, even if you're looking after two people.
- Carers Allowance is not paid in addition to a state pension.

Carers Credit

Carers Credit protects your National Insurance contributions if you can't work because of your caring responsibilities, but you are not claiming Carers Allowance for whatever reason.

- You have to be caring 20+ hours a week.
- You don't need to apply if you're already claiming Carers Allowance as your NI contributions automatically get paid.
- The person you care for doesn't necessarily have to be on a disability benefit, but you will need confirmation from a medical professional that they have care needs. When you apply fill in the 'Care Certificate' part of the application form.

If there are any hospital admissions keep the Carers Allowance Unit updated on 0800 7310297

Working Age Carers

Caring does not necessarily mean you have to give up work completely. Sometimes a few tweaks are all it needs for you to be able to care AND stay in the workplace. It's always worth having a conversation with your employer to see how your job and your caring can work together - for example, how you will make the time up if you need to take the person you care for to a medical appointment.

Check whether your employer has a Carers Policy. For example, some companies will give you a certain number of days of paid carers leave. Other companies will “match” annual leave for carers - i.e. if you need two days off because someone is in hospital, it will be one day of annual leave plus one day of carer leave. Ask your HR department if your company has a specific Carers Policy.

All UK employees have the right to ask for flexible working once they have been in post for 6 months. Employers do not have to agree, but they must give you a sound business reason for refusing. Examples of flexible working might include changing or reducing your hours, doing some of your hours from home, compressing your hours (i.e. working your full hours in fewer days) or job-sharing.

You have the right to take a “reasonable” amount of leave off to deal with an emergency with the person you care for. Your employer will decide whether this is paid or unpaid leave.

If you are considering giving up work to care full time there may be other things to consider such as the financial implications of losing your wage or the effect on your pension. Make sure you have explored all options, including the support available to you.



Council Tax Reduction

Adults with Severe Mental Impairment are disregarded for council tax purposes. So for example, if two adults are living in the house and one has Severe Mental Impairment, the other one would be treated as if they were living there alone and therefore get the single-occupancy 25% discount.

- A person might be considered Severely Mentally Impaired if they have dementia, Parkinson's, severe learning difficulties or have had a stroke.
- A doctor must certify that they are severely mentally impaired.
- The person must be eligible for a disability benefit.

Carers of an adult who is not their spouse or partner, this includes people caring for adult children, can be disregarded for council tax too.

- you must be caring for at least 35 hours a week.
- you must live with the person you care for.
- you must not be the spouse or partner of the person you care for, or their parent if under 18.
- the person you care for must be getting either the middle or higher rate of the care component of Disability Living Allowance, the daily living component of Personal Independence Payment, Attendance Allowance, Armed Forces Independence Payment or the highest rate of Constant Attendance Allowance



Lasting Power of Attorney (LPA)

We advise everyone to get a Lasting Power of Attorney or “LPA”. This allows you to decide in advance who you would want to make decisions on your behalf if you could no longer make them - someone you trust to do the right thing for you. This person is called your Attorney. You can appoint more than one.

You must have “mental capacity” when you set up an LPA, i.e. the ability to make your own decisions. You can amend your LPA at a later date as long as you still have “mental capacity”.

In England there are two types of LPA: Property & Finances, and Health & Welfare.

Once registered, with a Property & Finances LPA your Attorney can start doing things on your behalf straight away with your permission. With a Health & Welfare LPA, your Attorney can only make decisions on your behalf once a medical professional confirms you have lost “mental capacity”.

Without an LPA, in order for your loved ones to be allowed to make decisions on your behalf they must apply to be your “Deputy” via the Court of Protection.

Further information can be found at:
www.gov.uk/power-of-attorney



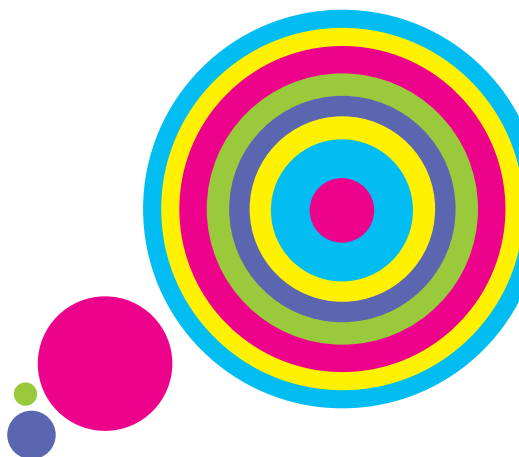
Wills

We strongly advise that everyone makes a Will. Most people who do find it reassuring to know that everything is sorted, and their estate (money, property and personal possessions) will go where they want. It's particularly important to take professional advice if you have been married before, if either of you has children from a previous relationship, or if your estate is likely to be subject to Inheritance Tax.

- Most people choose to have their Will drawn up and stored by a local solicitor.
- Will Aid Month, in November of each year, is when some solicitors will write your Will in exchange for a donation to charity. For more details, go to www.willaid.org.uk
- Free Wills Month takes place every March and October and lets those aged 55+ get a solicitor-drafted will for free - though it is hoped you'll leave something to charity. Go to www.freewillsmoth.org.uk

Living Wills

A living will is officially known as an Advance Decision. It lets you express your wishes to refuse certain medical treatments in future, even if doing so might lead to your death. For example some people might choose not to be resuscitated. It is legally binding, so the healthcare staff caring for you must follow your instructions. It is best to seek legal advice if you're thinking about an Advance Decision.



First Contact Plus

This website **www.firstcontactplus.org.uk** is your first contact for information, advice and support in Leicestershire. It gives advice on these areas:

- Falls
- Families and relationships
- Working, learning and volunteering
- Living independently
- Improving your health
- Feeling safe
- Money, debt and benefits
- Your home

There is also a form you can fill in online to make a referral on behalf of yourself or someone else, as long as they live in the county of Leicestershire. They will be contacted in due course by a member of the First Contact team.



Local Area Co-ordinators (LACs)

LAC workers are based in the community. They can help with:

You: thinking about how to make life better and looking at what you have to offer

Connecting with others: linking people together and helping you be a part of your community

Information: finding out about what's happening in your area and getting the right help for you where and when you need this

Taking action: helping you to make changes that will improve your quality of life

Signposting: offering advice about local services or community groups

Longer term support: working with you for longer periods when needed to help you achieve your goals and lead a happier life.

To see if there is a LAC worker where you live, go to:

www.leicestershirecommunities.org.uk/csi/local-area-coordination.html
or call: **07951 486 235**

Other Useful Information

Aids and adaptations for the person you care for

There is the option to go straight to a mobility shop and purchase your own aids, which is fine, but there are other ways. You could visit the Safe and Well website - www.safeandwell.co.uk/leicester/index.php You can call Adult Social Care on **0116 3050004** to ask for an Occupational Therapy Assessment. An O.T. will come out to your house and see what adaptations might make life easier and safer - for example grab rails, guide lighting or hoists to help you move the person you care for without hurting yourself. Up to a certain amount, these adaptations are done free. For more expensive changes, like converting a bathroom to a wetroom, the cared-for person will be financially assessed to see how much they should pay.

Wheelchairs

Most mobility aids suppliers will sell or rent a wheelchair. In the short term, wheelchairs can also be rented from charities like the Red Cross. If the wheelchair is going to be a long-term or permanent solution, it is worth having a proper Wheelchair Assessment to make sure a suitable model is selected. Obviously the person's size, weight, medical conditions and who will be pushing the chair all come into play. A wheelchair assessment can be accessed through your GP. They might supply you with an actual wheelchair or give you a voucher towards purchasing one from a specialist supplier.



Blue Badge

If the person you care for has mobility difficulties it is well worth applying for a Blue Badge. As well as allowing you to park in disabled bays, you can park on double yellows (if safe) for up to 3 hours and car parks might be cheaper or even free.

From August 2019, eligibility for a Blue Badge will also include some “hidden” disabilities such as dementia, autism or certain mental health conditions. There is a small cost for a Blue Badge, it lasts 3 years and to get one you go via Leicestershire County Council.

- Apply online at:
www.leicestershire.gov.uk/roads-and-travel/cars-and-parking/blue-badge-parking-scheme/apply-for-or-renew-a-blue-badge
- OR phone the Blue Badge Department on **0116 3050001**.

Radar Keys

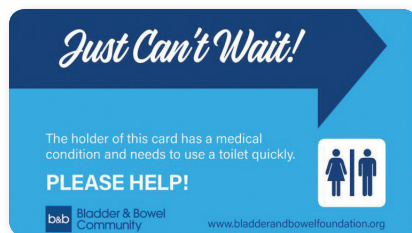
These keys give access to locked disabled toilets around the country. To get one, either phone 01395 265543 or

- Visit www.nationalkeyscheme.org.uk
- Email sales@radarkey.org

Just Can't Wait card

Developed by the Bladder and Bowel Community, this small card allows you to quickly and discreetly explain that the cardholder has a medical condition that means they need to access a toilet quickly. Although shops or other businesses are not obliged to let you use their facilities, in practice most places will be helpful.

Just Can't Wait cards can be ordered online at: www.bladderandbowel.org



Jointly

This brilliant smartphone app developed by Carers UK can connect two or more users who are sharing the care for someone. It has group messaging, a shared calendar, and medication and task managers. The idea is that everything gets done and nothing gets done twice. It is available for both Apple and Android smartphones.

Jointly can be accessed for free via LCC at this website:

www.leicestershire.gov.uk/adult-social-care-and-health/looking-after-someone/find-someone-to-talk-to-about-caring

Utilities

It's worth telling the companies who supply your gas, electricity and water about your caring situation. Different companies have different schemes that may help. For example, if you care for someone with a condition that means they have to use a lot of water, Severn Trent can cap your bill at the "average" amount for a similar household.

Discounts and reductions for Carers

Various venues such as cinemas, theatres, theme parks and leisure centres offer free or discounted admission for carers. It's worth checking online or by telephone before you go. Venues may ask for proof of disability such as a Blue Badge, doctor's letter or proof of receipt of PIP, DLA or Carers Allowance. We would advise making photocopies rather than taking along your precious original documents.

ICE - In Case of Emergency

ICE stands for In Case of Emergency, if you add it as a contact in your mobile phone contacts list, people like the Police and Ambulance will know who to contact in an emergency. You can add more than one person - ICE1, ICE2, ICE3 etc.

Carers Checklist

- ☐ Register yourself as a carer at your GP surgery

- ☐ Check to see if you're eligible for any benefits

- ☐ Carers Assessments
See what help or support may be available to you as a carer

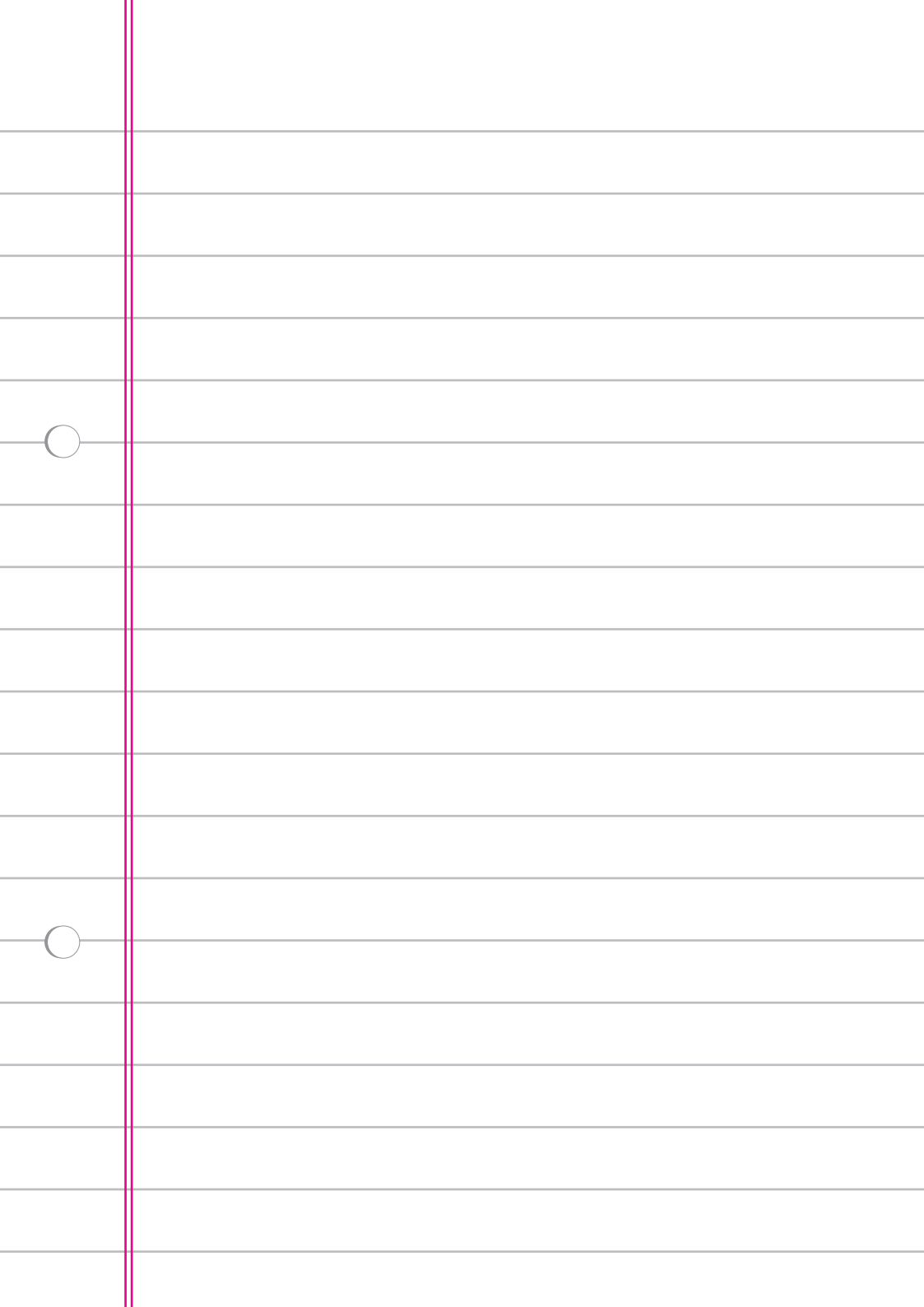
- ☐ Emergency Plan in place
In case you become ill or unable to care for your loved one

- ☐ L.P.A. & Wills
Make sure your legal affairs are in order

- ☐ Call Social Services if you need help looking after
your loved one including any aids or equipment



My notes



If you need medical help fast, but it is not life threatening – call

NHS

What is ?

If you need medical help fast but it's not a life-threatening situation, you can now call the new NHS 111 number. When you call 111, a trained adviser will ask you questions to find out what's wrong, give you medical advice and direct you to someone who can help you, like an out-of-hour doctor or a community nurse.

If the adviser thinks your condition is more serious, they will direct you to hospital or send an ambulance. If you don't speak English, tell the adviser what language you want to speak and they will get you an interpreter. You can call 111 any time of the day. The call is free, from landlines and mobiles.

When do I use it?

You should only call 999 in an emergency – for example, when someone's life is at risk or someone is seriously injured or critically ill.

Call 111 if you need medical help fast, but it's not life-threatening – for example, if you:

- think you need to go to hospital
- don't know who to call for medical help
- don't have a GP to call
- need medical advice or reassurance about what to do next

For health needs that are not urgent, you should call your GP.

If a health professional has given you a number to call for a particular condition, you should continue to use that number.

Who can use it?

The NHS 111 number is currently only available in certain areas of England.

If you're outside of these areas, you should call NHS Direct on 0845 4647.



**when it's less
urgent than 999**

More information

For more information on where the NHS 111 service is available or to get this leaflet in other languages, visit www.nhs.uk/111

Useful phone numbers



Leicestershire Support for Carers

01858 468543

Leicestershire County Council - Adult Social Care

0116 3050004

Leicestershire County Council

Out of Hours (emergencies)

0116 2551606

NHS 111 (medical advice and reassurance 24 hrs a day)

111

Attendance Allowance Unit

0800 7310122

Carers Allowance Unit

0800 731 0297

Carers UK

020 7378 4999

Age UK Leicestershire and Rutland

0116 299 2233

Care Home Selection

0800 008 7193

Samaritans

08457 909 090

Call: 01858 468543 Email: maureen@supportforcarers.org Visit: www.supportforcarers.org



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REGULATOR**



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Registered charity number 1141274