

CARER'S INFORMATION HELPING YOUR LOVED ONE MANAGE THEIR RENAL CONDITION



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HELPLINE **0800 169 09 36**

www.kidney.org.uk

What does providing unpaid care mean?

Families and friends sometimes help or support someone they know who is ill, disabled or who has become frail e.g. a family member, a close friend or neighbour. A carer is someone who, informally and without payment, cares for a friend, family member, neighbour, or in fact anybody who could not manage without their help. This could be due to age, physical or mental health issues, substance misuse or disability. In this context, being a carer does not refer to professional carers who are paid to care and who may, as part of their job, accompany someone to hospital, as for example, agency workers or care home staff may do. Carers come from all walks of life, can be all ages and are in different caring situations; often they have other commitments such as work, family and study.

This support might include helping someone in their own home or over the phone and can include things like:

- Helping someone with medication, reminding them, collecting it or helping to give medication.
- Providing daily support such as helping them move around the house, making meals for them, cleaning or other chores.
- Emotional support like helping someone manage anxiety.
- Helping manage money, paid care or other services.
- Making appointments, arranging care.
- Helping someone to wash, dress, bathe or helping someone to eat.
- Or it could be providing much more complex care such as supporting them to record observations such as pulse, blood pressure or sugar levels.
- It could be assisting in home dialysis.

If you do any of these things, and do not receive payment for doing so then that means you are an unpaid carer.

Helping your loved one to manage their renal condition:

If your loved one is a renal patient, there may be several things that might create a challenge or tensions between you. The routine of home or hospital-based dialysis might mean limits for your lifestyle and the things you can enjoy together. Speak to your renal team about options and support for managing this and things such as going on holiday.

Your loved one might need to manage the types of foods they eat, how much fluid they drink, or need to take routine medications to manage their kidney failure or transplanted kidney. It may be a source of tension if your loved one struggles to keep up with these requirements, and you may feel the need to remind them where you can, try to encourage your loved one to do things for themselves, and not doing things for them will encourage their sense of independence and personal responsibility.

It's helpful if you connect with other families of renal patients to understand the shared frustrations. There may be a local Kidney Patient Association in your area, the National Kidney Federation will have details.

It is also possible, that at some point your loved one might decide continuing with treatment is difficult, and they wish to discontinue treatment and pass away peacefully. It's a hard conversation to have, but it can be helpful to have conversations like this earlier on, so that people can share what their wishes would be if those future circumstances were to arise. The National Kidney Federation produce a leaflet called End of Life Care which may be of some help.

Why you need to be identified as a carer

Lots of people provide care but the vast majority do not see themselves as carers. Many see the care they provide as a normal part of their role as a husband, wife, partner etc. It is important to look after yourself, it is not only important for you but it is also important for your loved one. You cannot give to others if you are not taking care of yourself.

Caring can be very rewarding but also very demanding, it can affect your physical and mental health and emotional wellbeing. Many carers are trying to work, and study look after other family members in addition to their caring responsibilities.

It is important to make sure carers are aware of support available as early as possible.

Carers Act

The Care Act 2014 came into effect in April 2015 and replaced most previous laws regarding both carers and people being cared for.

Under the Care Act, you are entitled to a carers assessment where you appear to have needs for support. You will be entitled to this support if you meet the national eligibility criteria.

The person you care for is entitled to a needs assessment if they appear to have needs for care and support.

Local authorities are allowed to arrange for other organisations such as charities or private companies to carry out assessments.

Each local authority will have a website giving information of where to find advice and local support resources.

Carers and Work

If you're working as well as caring for someone, it can seem like there simply aren't enough hours in the day. But there are lots of adjustments you can make to ensure that you can continue working and be a carer. The first step is to think about how you'd like to balance working with your caring responsibilities. It's good to have a clear idea about this if you need to have a conversation with your employer about flexible working. Flexible working can mean part-time, flexitime, compressed hours (working your agreed hours over fewer days), job-sharing or homeworking.

A new piece of legislation, which is expected to come into force on 6th April 2024 is The Carers Leave Act, designed to support employees who are also unpaid carers.

It creates an entitlement for employees to take leave in order to provide or arrange care for a dependant with a long-term care need regardless of how long they have worked for the employer. Employees are entitled to up to five days of unpaid leave per year to support their caring responsibilities. This can be taken in full days, half days or hours.

Registering as a Carer

If you are looking after someone who has a disability, mental health condition, or long-term illness, you can register as a carer with:

Your GP, DWP, Local Council, Local Carers Service, Employer, Schools, Universities or Colleges. your energy provider. It is a good idea to ask if the person you care for can be added to the register too, particularly with the GP

Carers Allowance Benefit

If you spend a lot of time looking after someone with an illness or disability, you may be entitled to extra money in the form of a benefit called Carer's Allowance. You do not have to be related to, or live with, the person you care for. You do not get paid extra if you care for more than one person. If someone else also cares for the same person as you, only one of you can claim Carer's Allowance.

If you have to give up working to care for someone you may be worried that not paying National Insurance will lower your State Pension in the future. Carer's Credit is a weekly benefit for carers to fill the gaps in your NI contributions. If you are already claiming Carer's Allowance you will automatically get Carer's Credit if not you should apply for it.

Carers Discounts

Registering as a carer can open many doors to discounts for travel, days out, leisure activities, educational courses, local business discounts depending on whereabouts in the country you are. See your local council website for more details.

Psychological effects.

Young or old, many of us find ourselves caring for our partner. The impact and implications this has will vary depending on our age, life stage, our own health, their diagnosis (and impact) and many more factors

Taking on the responsibility of caring for our partner can feel different to looking after a parent, child or another relative. It can shift the balance in our relationship, change our anticipated future plans and dreams, and bring a strange duality to our role, as we shift between partner and carer.

Common Issues

Managing Care

Caring for a partner often involves managing personal tasks like bathing or toileting, this can be challenging for both parties as the partner may feel embarrassed needing help, and the caregiver may need time to adjust. However, there's no shame in it, and mutual understanding can ease the process. It's not uncommon to use a touch of humour to help lighten the mood.

Loss of Sexual Intimacy

Sex can be an important part of a close relationship. Many chronic illnesses cause problems with sexual function and disrupt how we connect with our partner. As caregivers, our own sexual desire can also fluctuate. The transition from caregiving tasks to intimate moments can be challenging, and it's normal to feel exhausted or still be processing the situation. It's important to communicate openly about these feelings with your partner and seek support if needed. It is still possible to enjoy intimacy with our partner. Non-sexual physical affection, such as cuddling, kissing, and holding hands, can serve as alternative expressions of intimacy.

Personality Changes

When a loved one receives a life-changing diagnosis, they experience a range of emotions, including grief, denial, and anger. It's not uncommon for individuals to vent these feelings on those closest to them. It's important to remember that their words may be a reflection of their fear and anger, or even a symptom of their illness, rather than a personal attack. However, it's also valid to acknowledge that such unkind and harsh comments can still cause significant hurt.

A Change in Roles

Adjusting to new roles following a loved one's life-changing diagnosis can initially be challenging. However, this situation also presents an opportunity to reframe our perspective and view it as a new challenge. We might find satisfaction in accomplishing tasks like changing a flat tyre or cooking a roast dinner from scratch for the first time, and may even enjoy acquiring and honing new skills. It's also completely normal if we don't feel positive about these changes - fatigue and emotional exhaustion can make it difficult to think clearly. Indeed, adapting to role changes can be challenging, especially when our partner has been accustomed to doing things in a certain way for a long time. Our spouse may feel that our attempts at domestic tasks don't meet their expectations. They might also express dissatisfaction with how we manage bills and administrative tasks.

Loss of Income Financial Worries

Financial concerns can significantly strain our relationships. Anxiety may arise from potential income loss if our partner becomes unable to work. We might also have to quit our jobs or cut down our working hours to concentrate on caregiving, which can cause tension at home.

If our partner is affected by a disability or health issue that hinders their work capacity, they might qualify for certain benefits. Additionally, individuals providing care are also eligible for financial assistance.

Loneliness

Depending on the nature of our previous relationship and the diagnosis we're facing, feelings of loneliness can certainly emerge. Some of us might feel as though we're losing our closest companion. In some cases, we may become so engrossed in caregiving and adjusting to the new circumstances that we distance ourselves from our friends and family, or we might perceive them as distancing themselves from us.

Resentment

Resentment is a common feeling experienced by unpaid carers. It is important to acknowledge these feelings as they can lead to poor outcomes for both the carer and the person being cared for. Once you have recognised these feelings you can often work out what is triggering them and find ways to improve the situation.

Taking Time Out

Doing something enjoyable or relaxing can be very helpful when you have a caring responsibility.

If you're able to, make time for something like an exercise group or an evening class. Taking part in an activity you enjoy will give you the opportunity to do something for yourself it's important that you have your own interests and make time to pursue them where you can.

Taking a break also known as respite is essential for your physical and mental wellbeing. Respite offers an opportunity for rest and rejuvenation, enabling you to partake in enjoyable activities. Again, this is something your Local Authority can discuss with you.

Written by NKF Helpline

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The National Kidney Federation cannot accept responsibility for information provided. The above is for guidance only. Patients are advised to seek further information from their own doctor.

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A FEDERATION OF MORE THAN FIFTY PATIENT CHARITIES, SUPPORTING KIDNEY PATIENTS & CARERS

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