

What I tell my patients about benefits and entitlements

Most patients (or clients, as renal social workers tend to call them) are in a state of denial and disbelief when they are first diagnosed with chronic kidney disease; even more so, sometimes, when they are nearing the need for dialysis. Conflicting emotions, such as awareness of mortality, family pressures, insecurity and fear of changes in lifestyle make it difficult to take in all the implications. There is a need for repetition and reassurance and a gentleness as the news sinks in. If there is acute renal failure leading to a chronic condition with no preparation, this is even more difficult because of the immediate hospital treatment. For those who have time to consider and attend predialysis groups and meet members of the multidisciplinary team, the renal journey is possibly easier, although the implications remain the same.

Applying for benefits

Those with money have choices in life, but when this is substantially reduced there are enormous repercussions for some. This depends on the age of the patient, whether there is family support, what sort of job they have if they are working, what other diseases, and where and how they live. Each person is unique and no circumstances are exactly the same. When people are referred, we try to look at the whole picture and offer whatever is needed, such as counselling, practical advice, networking with other agencies and trying to get the best possible deal for each individual and family. Some years ago, I sent out some quality of life questionnaires and, while the desire for better health and choice of lifestyle came top of patients' priorities, the need for extra financial support came a close second and was indeed connected.

Information about what financial help is available may be obtained from several different sources, and it is always sensible to double-check. In some areas there are good welfare rights groups. The Citizens Advice Bureau has up-to-date information and can be particularly helpful with any debt problems. There are specific kidney organisations – particularly the National Kidney Federation (NKF), which provides very helpful

Getting financial advice can help to overcome your concerns about lifestyle changes following diagnosis



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advice on its website and has a helpline. Details on some of these organisations are listed later.

There is an excellent Disability Rights Handbook produced by the Disability Alliance each year. The Department for Work and Pensions (DWP) provides information on what allowances are available and has a website (www.dwp.gov.uk). It is responsible for most of the help available for disabled people. The day-to-day running of the benefits system is undertaken by Jobcentre Plus, the Pension Service, the Disability and Carers Service, the Child Support Agency and the UK Debt Management Office. Disentangling who does what is not always easy.

Not everyone needs to be told all the information and the most common forms with which we deal are Incapacity Benefit (see below), Disability Living Allowance (DLA) and Attendance Allowance (AA). I will discuss the DLA and the AA in greater detail at a later stage but will meanwhile list some of the other possible benefits.

A significant change this year has been the introduction of Employment and Support Allowance (ESA). This replaces Incapacity Benefit and Income Support paid on the grounds of

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incapacity. ESA started on 27 October 2008. It affects anyone making a new claim for benefits because of limited capability for work caused by ill health or disability on or after this date. A work capability assessment (WCA) will be used for everyone on Incapacity Benefit, Severe Disablement Allowance or Income Support from 2010, and from 2009 for those under 25. Claimants receive a basic rate for the first 13 weeks, the same as Jobseeker's Allowance, and are then given work-focused interviews. If people score enough points in the WCA, they then move on to a higher rate of ESA, otherwise their ESA stops. A separate test will be carried out at the same time, to decide whether they have limited capability for work-related activity.

All this has important implications for renal patients. While it does not affect current recipients of benefits, if they stop receiving Incapacity Benefit, Severe Disablement Allowance or Income Support for more than 12 weeks then they are counted as new applicants if they apply again in future.

Some common benefits

Here, then, are some of the benefits that I might explain to people when I see them either at home or in hospital.

Statutory Sick Pay

You would receive Statutory Sick Pay if you were working for an employer and paying National Insurance contributions when you became sick.

Incapacity Benefit

Incapacity Benefit is available if you were not working when you became sick, you were self-employed or you have been sick for more than 28 weeks.

Haemodialysis patients can claim Incapacity Benefit for the days they are unable to work because of having treatment.

Income Support

Income Support is available if you cannot get Statutory Sick Pay or Incapacity Benefit, or if you are eligible for these but still do not have an income large enough to live on.

Disability Living Allowance

This is available if you are aged over 16 and under 65 and need help looking after yourself or getting around. There are three components: lower-rate care, middle-rate care and mobility.

Attendance Allowance

If you are aged over 65 and need help looking after yourself or getting around. There is no mobility component, but you can get extra funding if you need help at night.

Disabled Person's Tax Credit

If you are aged 16 or over and working an average of 16 hours a week or more and are restricted in the type of work, number of hours or amount you can earn because of illness or disability.

Home Responsibilities Protection

If you are unable to pay National Insurance contributions because you are caring for someone.

Carer's Allowance

This was formerly called Invalid Care Allowance. If you are aged 16 or over and spending at least 35 hours a week looking after someone who is getting, or waiting to hear about getting, AA or DLA at the middle or highest rate for personal care.

Industrial Injuries Disablement Benefit

You can claim this if you became disabled as a result of an accident at work, or if you develop a disease known to be a risk of a job you have done, including deafness.

Housing Benefit

You can claim this if you are on a low income and paying rent. This is an income-based benefit and is not dependent on you having an illness.

Council Tax Benefit

If you are on a low income and paying Council Tax you may qualify for a disability reduction. At least one of the following conditions must also be met.

- You have an additional bathroom or kitchen needed by the disabled person.
- You have a room (other than a bathroom,

The financial impact of a kidney disease can be lessened by the benefits available to you



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kitchen or toilet) needed by and predominantly used by that person, such as a room used for home haemodialysis or storage of peritoneal dialysis fluid.

- You have enough space in your home for that person to use a wheelchair indoors.

Help with NHS health costs

There can be charges for some treatment from the NHS. The NHS has produced a leaflet, which outlines information about who does not have to pay charges and also explains the help you might get with costs if you are on a low income. You may be eligible for help with:

- NHS prescriptions
- NHS dental treatment
- Sight tests
- Glasses and contact lenses
- Travel costs for treatment by a consultant.

Travel costs

Patients who are travelling to hospital for treatment can be reimbursed for travel costs if they are on Income Support, Income-based Job Seeker's Allowance or Pension Credit Guarantee Credit. Incapacity Benefit or DLA do not count, as they are not income-related. Reimbursement is also available if you are entitled to an NHS tax credit exemption certificate.

Prescription charges in the UK

Both haemodialysis and peritoneal dialysis patients can now claim for free prescriptions. Any patient who has a permanent fistula that requires a surgical dressing or an appliance is entitled to medical exemption if they have completed application form FP92A and a doctor has signed the form to confirm the condition (in this context, 'permanent' is taken to mean 'intended to last indefinitely'). Whether a dialysis patient has a permanent fistula that requires a surgical dressing or appliance is a matter for their doctor's clinical judgement. The criteria should be met where there is a clinical need for a permanent fistula to be covered by a surgical dressing (for example, between haemodialysis treatments) or by an appliance (such as a catheter for peritoneal dialysis).

Water charges

If you pay for your water on a meter and suffer from kidney failure requiring dialysis at home, and are on a low income or are part of a large family on a low income, you may be able to apply to have your bill capped – there is a fixed ceiling

Box 1. Contact details for kidney patients

■ **British Kidney Patient Association**

Bordan, Hants GU35 9JZ
Tel: 01420 472021. Fax: 01420 475831.
www.britishkidney-pa.co.uk

■ **Kidney Research UK**

King's Chambers, Priestgate, Peterborough PE1 1FG
Tel: 01733 704650. Fax: 01733 704699.
www.kidneyresearchuk.org

applied to your bill and however much water you use, your bill cannot go above the average figure for your area. An application should be made to your local water company under the 'vulnerable groups' tariff.

Local grants

Your local authority (council) may be able to help you with a grant for improving your home or making alterations for medical reasons. This is usually means-tested.

Government grants social fund

This is a discretionary fund for people in need and can be a grant or an interest-free loan to help people on Income Support, Income-based Jobseeker's Allowance or Pension Credit. There are crisis loans for people in immediate short-term need, even if they are not already on benefits.

Charities

Local kidney patient associations may be available to help with grants and holidays. The British Kidney Patient Association and Kidney Research UK can provide all sorts of financial help for everything from practical needs such as a washing machine to educational needs and holidays, at home and abroad. We (that is, Renal Social Workers or Kidney Patient Support Managers) usually help with the applications and write a report. Box 1 (above) has contact details for these organisations.

More details about Disability Living Allowance and Attendance Allowance

You are not usually entitled to these unless the illness has been for over six months for AA and three months for DLA.

Filling in these forms takes time and effort. Some of my work is spent advising and helping kidney patients with these and assisting with appeals when applications are turned down. There are numerous questions, some of which seem very repetitive. The mobility component is only



Box 2. Useful websites and details about who to contact for benefits advice

■ Benefit Enquiry Line (Department for Work and Pensions)

Tel: 0800 882 200.
N. Ireland tel: 0800 220 674.
Monday to Friday 8.30–6.30,
Saturday 9–1.

■ Form-filling advice helpline

Tel: 0800 441144.

■ Disability Benefits Unit

For advice on Disability Living Allowance and Attendance Allowance. Tel: 08457 123456.

■ Disability Alliance

Tel: 0207 2478763.
website: www.disabilityalliance.org

■ UK National Kidney Federation

Tel: 08456 010209.
website: www.kidney.org.uk

■ Citizens Advice Bureau

For free advice on many issues. Look in the phone book for your local branch.
website: www.nacab.org.uk
website: www.adviceguide.org.uk

■ The Pension Service

Government helpline for pension advice. Tel: 08456 060265.

■ The Blue Badge Network

Aims to help those with severe mobility problems. Contact your

local authority social services department for details.

Tel: 01384 257001.
website: www.bluebadgenetwork.org.uk/index.html

■ Help with health costs

website: www.dh.gov.uk/en/Healthcare/Medicinespharmacyandindustry/Prescriptions/NHSCosts/index.htm

■ Carers UK

Provides information and support for carers.
Tel: 0808 808777.
website: www.carersonline.org.uk

available for DLA. However, the allowances are not means-tested, and can be obtained whether or not you are working and they do not affect any income-related benefits, so it is well worth applying. (The care component is, however, taken into consideration if you have a care package from a local authority.)

It is important to be honest. Some people like to pretend they are better than they actually feel, while others may say they are worse! The DWP writes to your doctors for confirmation, so it is wise to consult them during the application. Sometimes the DWP sends round its own doctors to check on the information given. The NKF provides helpful guidelines on how to complete these forms. There are also important qualifying

benefits for the receipt of other benefits.

If a doctor says that a patient is likely to die from their illness within six months, the allowance can be expedited under special rules. In all cases the payment starts once the application has been received and, if approved, is backdated.

Claiming your benefits

This information is correct at the time of writing, but in this field the situation changes swiftly. Figures, such as the weekly amount you are entitled to under each benefit, have not been quoted as they change frequently.

All of us in the multidisciplinary team need to know how to advise our patients on financial difficulties. Kidney failure can change lives and is a family problem. Even where transplantation takes place and things seem a little more normal, there is always the anxiety of rejection and a return to the need for dialysis, but there is a lot of help available. Box 2 features contact details for organisations that you might find helpful. While not everyone has a computer, most have access to a telephone, so I hope all will be able to find out the information needed ■

Mary Braybrooke is a social worker who has worked with children and adults in eight local authorities for the last 50 years. She has worked with kidney patients since 1994 and now works part-time as a Kidney Patient Support Manager at the Churchill Hospital, Oxford. She would like to thank the National Kidney Federation for its helpful information.

Key points

- Patients with kidney disease, especially when newly diagnosed, can become overwhelmed by decisions they have to make and financial considerations.
- The impact of kidney disease on personal finances and lifestyle can be lessened by a series of benefits and entitlements that help kidney patients meet their costs.
- The new Employment and Support Allowance, launched in October 2008, will change the way benefit entitlements are assessed.
- There are many advice bodies, with websites and helplines, to help you ensure that you are up to date with your entitlements.



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