Deciding to care or continue caring for someone who is coming out of hospital and who can no longer care for themselves in the same way as before can be difficult. This factsheet explains your rights as a carer, the steps that should be followed and what to do if things go wrong. It applies to people living in Wales.

Contents

If the person you care for is in hospital .......................................................... 2
What should happen before the person I care for is discharged? ............... 4
What should happen on the day the person I care for is discharged? ....... 5
Following discharge .......................................................................................... 6
The carer’s assessment .................................................................................... 8
Discharge from a mental health facility .......................................................... 9
Important things to think about if the person you care for is in hospital . 12
Complaints ........................................................................................................ 13
Further help ..................................................................................................... 16
If the person you care for is in hospital

If the person you care for is in hospital you may be faced with important decisions. You may be considering taking on a caring role for the first time and don’t know what to expect. You may have already been caring for the person but their needs may have changed or increased.

One important thing to remember is that it is your choice whether or not you are willing and able to take on the caring role and the extent of the care that you may wish to give.

You will need to think about the amount and type of care you are willing and able to provide and what other help or support you may need. For example, you may be able to help with shopping and meals but feel you would like someone else to help with the personal care of the person you look after.

It is important for you to consider how your caring role is likely to affect your life and well-being including things such as your emotional and physical health, other relationships, finances and work or studies.

If you decide to take on a caring role, as soon as it appears that you may have a need for support you have a legal right to an assessment of those needs from the local council. This is regardless of the amount or type of care that you are willing to provide, your financial means or the level of support you may need.

You do not have to be related to or live with the person you care for to be entitled to an assessment. The council can do an assessment of your needs while the person you care for is still in hospital or once the person has been discharged.

If more than one of you are planning to take on and share the caring role then you are all entitled to an assessment. Carers Wales has a factsheet about assessments. You can request a copy by contacting the office or downloading it from our website.
Should I, as a carer, be involved in the discharge procedure?

Planning for a patient’s discharge starts as soon as the patient is admitted to hospital, so it is important to let the hospital staff know as early as possible if you are a carer or thinking about taking on this role.

Each hospital will have its own discharge policy based on guidance from the Welsh Government. For more information, please see Welsh Health Circular; Hospital Discharge Planning Guidance (WHC 2005 035) or Welsh Health Circular: Implications of the Social Services and Wellbeing (Wales) Act 2014 for Health Boards and NHS Trusts (updated April 2016).

The guidance emphasises the importance of involving the patient and their carers at all stages of the discharge planning. You can request a copy of the hospital’s discharge planning policy from the ward manager or your local Community Health Council.

Hospital wards can sometimes seem like busy or intimidating places and you may feel pressure from the hospital or the patient to get the person home quickly. However, it is important that your views are being taken into consideration and the person is not being discharged before services are put in place.

If the patient lacks mental capacity you may be able to make certain decisions about health and welfare matters if you have a Lasting Power of Attorney (LPA). If there is no LPA the law requires, professionals to act in the ‘best interests’ of the person you care for and you should be involved in the decision making process.
What should happen before the person I care for is discharged?

**The discharge assessment**

The discharge assessment, which is to see if the person you care for needs support once discharged might be carried out by a multidisciplinary team of health and social care professionals. This is to avoid duplication and multiple assessments being carried out.

The assessment should look to see whether the person you care for is eligible for any intermediate or reablement care, NHS continuing healthcare, other NHS services and/or community care services from the local council. When the person you care for is nearing their expected date of discharge the following steps should be taken:

- An assessment should be carried out to see if they are medically fit to be discharged.
- A discharge assessment should be carried out to see if they need support once discharged.
- A carer’s assessment should be carried out (or at least arranged) to see whether you need support once the person you care for is discharged.
- If eligible for services, a care plan is drawn up setting out what services should be provided.
- The support outlined in the support plan (for the person being cared for) and the support plan (for you) should be put in place.
- An assessment for NHS continuing healthcare should be carried out where it appears there may be a need for such care.
- A financial assessment should be carried out to determine any charges for services – the Care and Support (Charging) (Wales) Regulations 2015 and the Care and Support (Financial Assessment) (Wales) Regulations 2015 state that there is a maximum charge that you can be expected to pay for non-residential social services in Wales. To find out the current maximum charge contact Carers Wales or the Carers UK Helpline.
- The care plan is implemented.
What should happen on the day the person I care for is discharged?

On the day of discharge you and the patient should expect to be given both verbal and written information with details of any services involved and information about future treatment and care.

The information should be in a language and format suitable to you. It is common that people do not remember or understand all the information they are given so don’t be afraid to ask for it to be repeated or explained in a different way.

You and the person you care for should expect the following type of arrangements to be made for the day of discharge:

- appropriate transport should be organised if required
- you should both be given copies of the care and support plan for the person being cared for and the support plan for you (if you have been assessed)
- a discharge letter should be sent to the patient’s GP within 24 hours
- medication and any equipment needed at home should be dispensed to the patient, as well as instructions and information about its use
- any necessary support should be put in place to start on the day of discharge
- a discharge lounge (or similar space) should be available for use in the hospital while waiting for transport, medication etc
- if appropriate up to six weeks of free intermediate care should be put in place, this includes care in your own home.
**Following discharge**

**Intermediate care**

These are a range of services designed to promote faster recovery from illness and to prevent delays in discharge from hospital. These services can include nursing, occupational therapy or physiotherapy. Intermediate care can take place in a person’s own home, a day care facility or in residential care for up to six weeks. No charges should be made for the first six weeks of intermediate care services.

**Reablement services**

These are after-care services to help promote independent living and make it less likely that readmission to hospital is necessary. The focus is on working jointly with agreed goals to improve the patient’s independence and confidence and to reduce the need for longer term home care services. Reablement services are usually free for the first six weeks.

Following the initial six weeks of reablement a review of needs should take place and further home care arranged if required. These home care services are usually chargeable on a means tested basis and could be provided directly by the council or by means of a direct payment.

Medical equipment and incontinence products can be provided free on the NHS if the person you care for is assessed as needing such items.

**Palliative care**

Palliative care can be provided free on the NHS and is for people who have a health condition which is not expected to be cured by medical treatment. There is a difference between this and ‘terminal illness’ where death is expected to take place within a given period of time.

Palliative care will consist of pain relief and other appropriate medical care. It may take place in a hospice, residential care home or in someone’s own home.

Where the illness is thought to be terminal the individual may be ‘fast tracked’ for the provision of NHS continuing healthcare.
NHS continuing healthcare

NHS continuing healthcare is a package of care for those who have a 'primary health need' that is arranged or funded by the NHS. This package of care is provided outside the hospital setting and can be provided in the home of the person you care for or in a residential or nursing home.

The 'primary health need' is a nursing or other medical need which is not just incidental to services that the local authority could provide. For example, someone with a complex medical condition or conditions requiring specialist nursing care may qualify for NHS continuing healthcare.

There is no charge for NHS continuing healthcare services and while there is no time limit for services the patient’s eligibility will be regularly reviewed.

Community Care Services from the local council

Most people being discharged from hospital won't need or be eligible for NHS continuing healthcare. Instead they should have an assessment from the local council to decide whether they are eligible to receive any help or support.

Support could include things like equipment or adaptations to the home or a care worker to help provide personal care etc. It will be important that if the person you care for or intend to care for gives consent that you are involved in this process.

The local council can at this stage with both your consents combine the person’s needs assessment with an assessment of your support needs if it considers that it is beneficial to do so. They must consider your views and the extent to which you are willing and able to provide care and any personal well-being outcomes that you wish to achieve.
The carer’s assessment

Where it appears that you may have needs for support the local council is under a duty to offer an assessment to decide whether you are eligible for any support. If you are assessed as needing support these services could be provided directly to you or to the person that you look after, which in turn would help with your caring role.

The duty to assess applies regardless of the council’s view of the level of support you may need, your financial resources or the financial resources of the person that you care/intend to provide care for.

The assessment must include the extent of the care that you are willing and able to provide and are willing and able to continue to provide. It must also take into account and consider whether or not the caring role will impact on your health and also have regard to your own personal well-being and any outcomes that you wish to achieve.

The assessment must consider a number of things including whether you work or wish to work, whether you are participating or wish to participate in education or training, or whether you wish to participate in leisure activities.

A local council when carrying out an assessment must involve you and where feasible the person you look after or intend looking after. Your carer’s assessment should cover:

- your caring role and how it affects your life and well-being
- your health – physical, mental and emotional issues
- your feelings and choices about caring
- work, study, training and leisure
- relationships, social activities and your goals
- housing
- planning for emergencies

For more information on the different types of assessment read our online information or download our factsheet on assessments. You can also
Discharge from a mental health facility

The Mental Health (Wales) Measure 2010 provides for the assessment and treatment of people with mental health problems and deals with how patients access and receive treatment in Wales. It allows people who are voluntarily having treatment for mental health problems in Wales the right to advocacy if they so wish.

The law does not deal with compulsory admission and treatment of individuals, these remain matters for the Mental Health Act 1983.

Care Coordination and Care and Treatment Planning

For patients who have been assessed as requiring treatment within secondary mental health services (those which are delivered through hospitals) the Measure places a duty on health services to appoint a care coordinator and put in place a written Care and Treatment Plan. The care coordinator will be responsible for coordinating the provision of mental health services and working with the patient, their carers and service providers.

When developing the Care and Treatment Plan the care coordinator should treat you as an equal partner in the care of the person that you care for. Your views should be taken into account where it is practicable and appropriate.

They will also be responsible for keeping in touch with the patient and reviewing and revising the Care and Treatment Plan. They will act as the principle source of information and will ensure that the patient is involved and engaged as much as possible in the planning process.

When formulating the Care and Treatment Plan care coordinators should focus on the needs of the patient, rather than think about the existing services that could be used.

The Care and Treatment Plan should be based on a recovery approach and not be limited to the specialist mental health services available.
Consideration should also be given to other services such as leisure, education, employment, training and other services offered by the voluntary sector.

Engagement with carers

Regulations in the Mental Health (Wales) Measure 2010 state that care coordinators should take all practicable steps to consult with any carers who may have a caring relationship during the preparation or review of the care plan.

Before any consultation with you takes place, the care coordinator has to take into account the views and wishes of the patient whether they want you to be consulted.

However, where the patient has indicated that they do not wish you to be consulted the care coordinator may still consult against the patients' wishes provided that they have given due consideration to the views of the patient.

The care coordinator can also decide whether to withhold a copy of the plan, or provide a copy of part of a plan, to you, if they believe that it is in the patient’s interests to do so. Where it is decided that consultation or sharing of the care plan with you should not take place it will be good practice to record the reasons for the decision and it should be kept under review.

Assessments of Former Users of Secondary Mental Health Services

This part of the Measure enables individuals who have been discharged from secondary mental health services, but who subsequently believe that their mental health is deteriorating to be able to refer themselves back for assessment to secondary mental health services without having to go elsewhere for referral first.

The entitlement to make the request for assessment lies only with the person who was previously the patient. No other person can make the request e.g. a carer, unless they are a donee or deputy under the Mental Capacity Act 2005.
There is a three year time limit for the person making the request. If they have been discharged from secondary mental health services for over three years then they would need to go back to primary care for assessment and referral.

**Mental Health Advocacy**

The Measure created an expanded statutory scheme of independent mental health advocacy, both for patients subject to compulsion under the Mental Health Act 1983 and for those informally (voluntary or informal) patients. Help and support should therefore be available for all in-patients to help them make decisions and choices about their care and treatment.

**Patients detained under a section of the Mental Health Act 1983**

If you are the patient's nearest relative and they are in hospital under a Section 2 or 3 of the Mental Health Act, you can give notice that you wish to discharge the patient. This must be done in writing and addressed to the Mental Health Act managers in the hospital. A responsible clinician can ‘bar’ this notice if they feel there would be a risk of the patient harming themselves or others.

Most mental health facilities will have an Independent Mental Health Advocate (IMHA) available for you to speak to about this. You can also contact Mind and Hafal for advice. ([Hafal@hafal.org](mailto:Hafal@hafal.org))

**Support following discharge: Community Mental Health Services**

If the person you care for is being discharged from a mental health facility they will usually be under the care of a Community Mental Health Team (CMHT). The services provided by CMHTs will vary in different parts of the country but could include Community Psychiatric Nurses, Social Workers, Occupational Therapists, Support Workers and Day Services. The patient may also be eligible for Section 117 Aftercare services.

**Section 117 Aftercare**

If the patient has been detained under certain sections of the Mental Health Act, they have a right to aftercare services through Section 117. This applies to people who have been in hospital for treatment under Section 3,
under a Section 37 (with or without restriction order) or following a transfer from prison under Section 47 or 48.

Aftercare services are designed to reduce readmission to hospital and in addition to the care at home services mentioned could also include residential care. Importantly there is no charge for aftercare services under Section 117.

**Important things to think about if the person you care for is in hospital**

**Benefits**

It is important to notify the relevant benefit office that the person you care for is going or has gone into hospital, as this may affect their benefits as well as your own.

If the person you care for was 18+ when they went into hospital then some benefits such as Disability Living Allowance (DLA), Personal Independence Payment (PIP) or Attendance Allowance will stop if the person you care for has been in hospital for more than 28 days.

Stays in hospital or a care home which are separated by 28 days or less are added together when working out when the benefit should stop (called the ‘linking rules’).

If the person you care for was under 18 when they went into hospital then their DLA or PIP can continue to be paid for the whole time they are there.

If the DLA, PIP or Attendance Allowance of the person you care for stops, your Carer’s Allowance will also stop. When the person you care for is ready to be discharged, inform the office dealing with the particular benefits to make sure that payments restart.

The person you care for may also be eligible for benefits at an increased rate if their care needs have changed. The rules relating to benefits are complex. For further advice and information, contact Carers Wales or Carers UK Helpline – see final page for details.
Help at work

If you are in paid work you may need to make some adjustments if the person you care for goes into hospital and/or when they come out of hospital. This could be anything from needing to make regular phone calls to check on them, through to taking off an extended period of leave. Most working carers have the following rights:

- the right to request flexible working
- the right to time off in emergencies
- the right not to be discriminated against or harassed under the Equality Act.

For more information on your rights in work visit [www.carersuk.org/work](http://www.carersuk.org/work) or contact Carers Wales or the Carers UK Helpline – see final page for contact details.

Complaints

Unfortunately there may be times when you need to make a complaint about a hospital discharge procedure, for example if you feel the person is being or was discharged without consultation and without the necessary support being in place.

When making a complaint, what matters is that you explain as clearly as possible what went wrong, what you would like to happen or what should have happened. You should complain as soon as you can.

Informal complaint

You may want to make an informal complaint by speaking to the discharge co-ordinator or social care professional immediately involved with the arrangements. This is often sufficient to resolve the matter.

If this informal approach does not resolve matters then you can use the NHS formal complaints process listed below.
Two stage formal complaints process

Either you or the patient can make the complaint about how you have been treated or the care provided. The complaint should normally be made within 12 months of the incident in question.

- **First stage complaint – local resolution**
  In Wales since April 2011 new arrangements have been put in place to deal with your complaints or concerns.

  You can request a copy of a leaflet called ‘Putting things Right’ from the hospital which gives information on how to make a complaint.

- **Second stage complaint – Public Ombudsman for Wales**
  If you are not happy with the response received to the complaint then you can take the complaint further by contacting:

  The Public Services Ombudsman for Wales,
  1 Ffordd yr Hen Gae, Pencoed CF45 5LJ
  Tel: 0845 601 0987
  Email: ask@ombudsman-wales-org.uk
  www.ombudsman-wales.org.uk

Complaints about the assessment for NHS Continuing Healthcare

If you are not satisfied with the way the NHS Continuing Healthcare initial assessment was carried out or the outcome of the assessment, make your complaint to the NHS professionals involved in making the decision. The NHS should work closely with you and the multidisciplinary team to resolve the decision informally whilst making sure that all the necessary assessments and procedures have been properly undertaken.

If the Health Board keeps to its original decision and you wish to challenge this further, you can ask to raise the complaint through the NHS complaints procedure. If you remain dissatisfied at the outcome you can then contact the Public Services Ombudsman for Wales (details above).

The Welsh Government has published a Public Information Leaflet called Continuing NHS Healthcare for Adults in Wales – WAG 10-033339 August 2010. You can request a copy by calling 029 2082 3683 or emailing wag-en@mailuk.custhelp.com
Assistance in making a complaint to social services

Community Health Councils (CHCs) in Wales provide advice and help if you have problems with or complaints about NHS services. You can contact the Board of Community Health Councils in Wales on 029 2023 5558 to obtain more information on your local CHC.

Complaints about social services

If your complaint is about social services, you should use the local authority’s statutory complaints procedure. Ask your local authority for a copy of their complaints procedure.

Once your complaint has been dealt with fully by the local authority concerned, if you are not happy with the outcome you can refer your complaint to the Public Services Ombudsman for Wales on 0845 601 0987.

Assistance in making your complaint to social services

You may be able to get assistance with making a complaint to social services from a local carers’ centre, citizen’s advice service or advocacy service. You can also speak to your local Assembly Member or local councillor.

Judicial review

In some cases an application for Judicial Review of a social services or NHS decision by the High Court may be possible. An application for judicial review must be made within a maximum period of three months so it is important to get legal advice as quickly as possible.
Further help

For information and advice contact the Carers UK Adviceline on 0808 808 7777 (open Monday and Tuesday, 10am to 4pm) or email advice@carersuk.org Information is also available on our website – visit www.carersuk.org

Other organisations

Board of Community Health Councils in Wales
Your local Community Health Council provides help and advice if you have problems or complaints about NHS Services in Wales. Ring the Board of CHCs or visit their website to find your local office.

w: www.wales.nhs.uk/sitesplus/899/home | t: 029 2023 5558
e: enquiries@waleschc.org.uk

Carers Wales

w: www.carerswales.org | t: 029 2081 1370 | e: info@carerswales.org

Public Service Ombudsman for Wales
Can offer advice and investigate complaints about public services in Wales.

w: www.ombudsman-wales.org.uk | t: 01656 641150 / 0300 790 0203
e: ask@ombudsman-wales.org.uk

Equality Advisory Support Service
The helpline advises and assists individuals on issues relating to equality and Human Rights across Wales, England and Scotland.

w: www.equalityadvisoryservice.com | t: 0808 800 0082

Older people

Older People’s Commissioner for Wales
Can provide help and support for older people and put them in touch with organisations who can help.

w: www.olderpeoplewales.com | t: 08442 640670 / 029 20445030
e: ask@olderpeoplewales.com
Age Cymru
Are able to offer free help and advice for older people on a range of topics.

w: www.ageuk.org.uk/cymru | t: 08000 223444 / 029 2043 1555

Children

Children’s Commissioner for Wales
Can offer support to children and young people and help them find out about their rights.

w: www.childcomwales.org.uk | t: 01792 765600 / 01492 523333 / 0808 801 1000 (number for children & young people)
e: post@childcomwales.org.uk

Children in Wales
Charitable organisation that promotes the interests of and takes action to identify and meet the needs of children, young people and their families in Wales.

w: www.childreninwales.org.uk | t: 029 2034 2434
e: info@childreninwales.org.uk

Contact a Family
A national charity that supports the families of disabled children.

w: www.cafamily.org.uk | t: 0808 808 3555 / 029 2039 6624
e: cymru@cafamily.org.uk

Legal help

Citizens Advice Cymru
Provides free, independent, confidential and impartial advice.

w: www.citizensadvice.org.uk/wales/ | t: 03444 772020
Mental Health

Hafal
Work with individuals recovering from serious mental health illness and their families.
w: www.hafal.org | t: 01792 832400 | e: Hafal@hafal.org

Mind Cymru
Provide advice and support to anyone experiencing a mental health problem. w: www.mind.org.uk | t: 0300 123 3393 / 029 2039 5123 e: info@mind.org.uk

As well as these listed above, there may also be condition specific charities that may be able to help such as Parkinson's UK, Stroke Association, Alzheimers Society, National Autistic Society, etc.

There are also many support groups and organisations ready to help locally. Visit www.carersuk.org/localsupport to see what is available where you live.

Benefit helplines

Attendance Allowance
t: 0800 731 0122 (textphone: 0800 731 0317)

Carer's Allowance
t: 0800 731 0297 (textphone: 0800 731 0317)
www.gov.uk/carers-allowance

Disability Living Allowance
- If you were born on or before 8 April 1948:
t: 0800 731 0122 (textphone: 0800 731 0317)
- If you were born after 8 April 1948:
t: 0800 121 4600 (textphone: 0800 121 4523)
For Jobseekers Allowance, Income Support and Employment and Support Allowance:

Jobcentre Plus
New claims t: 0800 055 6688 (textphone: 0800 731 7339)
Existing claims t: 0800 169 0310 (textphone: 0800 169 0314)

Pension Credit
t: 0800 731 7898 (textphone: 0800 169 0133)

Personal Independence Payment
New claims t: 0800 917 2222 (textphone: 0800 917 7777)
Enquiry line t: 0800 121 4433 (textphone: 0800 121 4493)

Tax Credits
t: 0345 300 3900 (textphone: 0345 300 3909)
This factsheet is designed to provide helpful information and advice. It is not an authoritative statement of the law. We work to ensure that our factsheets are accurate and up to date, but information about benefits and community care is subject to change over time. We would recommend contacting the Carers UK Helpline or visiting our website for the latest information.

Give us your feedback on this factsheet by emailing your comments to info@carersuk.org
This factsheet was updated in April 2019. Next review due November 2019.

Carers UK Helpline
For expert information and advice about caring.

📞 0808 808 7777
(Monday – Tuesday 10am-4pm)
@email advice@carersuk.org

Carers UK
20 Great Dover Street
London SE1 4LX
020 7378 4999
info@carersuk.org

Carers Wales
029 2081 1370
info@carerswales.org

Carers Scotland
info@carerscotland.org

Carers Northern Ireland
028 9043 9843
info@carersni.org

Carers Wales is part of Carers UK working together to make life better for carers.

Caring will affect us all at some point in our lives.

With your help, we can be there for the 6,000 people who start looking after someone each day.

We're the UK's only national membership charity for carers: join us for free at carersuk.org/join

We're both a support network and a movement for change.

Visit us at our website to join us, help us or access more resources: carerswales.org

This information can be requested in large print or as a text file.