

Preparing to Leave Hospital

If your wife, husband, partner, child, relative or friend is about to leave hospital they may need support and care when they get home, and you may be about to become a 'carer' for the first time.

Or, if you were caring for that person before, you may now face changes to your caring role. Either way this can feel like a confusing and difficult time.

This folder sets out to help you. It contains information on:

- what you can and should expect to happen when a person is discharged from hospital
- services which can support you and the person you care for
- contact points where you can get more detailed information and further support

The information is divided into six sections.

- Section 1: Before Leaving Hospital – Discharge Planning
- Section 2: After Leaving Hospital – Services in Your Community
- Section 3: Finances – Costs and Benefits
- Section 4: Being A Carer – Support for You
- Section 5: Where Now? – Useful Contacts
- Section 6: Checklist – Asking Questions

Edinburgh Carers Council has a range of leaflets which offer specific information to carers of people with mental health problems. Contact them on 0131 554 5153 for further information.

Before Leaving Hospital – Discharge Planning

What is a Discharge Plan?

As soon as people are admitted to hospital a process of planning should begin to find out what services and support they may need when they leave. By the time they leave hospital a clear discharge plan should be in place.

This planning process should ensure that when people leave hospital they and, with their permission, you as their carer, know about the following.

- Their medical condition

This should include any information on treatment, medication and future medical appointments. It should also include the names of the person's GP, Consultant and Named Nurse.

- Services and support

This should include information on the services that have been agreed and that will be in place for the person returning home, for example, home help and community nurse. It should also include information on local points of contact and where needed specialist information eg. Parkinson's Disease Society, local carers project.

How is a Discharge Plan Planned?

If the person needs to be cared for and supported for the first time or, if their care and support needs have changed, discharge planning will be important to make sure the right support and services are put in place. It is important that the patient and, with their permission, you as their carer should be involved in decisions and choices about their care.

It may be that services are already in place for the person and for you, as their carer. If this is the case the main issues for discharge planning are making sure that services will continue as before when the person comes home, and that there is clear information about their medical condition and treatment.

The following key people are always involved in the discharge planning process.

Named Nurse

They are the main contact person while the patient is in hospital, overseeing the care provided and plans made for leaving hospital.

The Consultant

They decide what medical care should be provided and decide when the patient is well enough to be discharged from hospital.

Pharmacist

They provide the medication required for the patient and information on when and how it should be taken. They can contact your community pharmacist to provide information on any changes to the medicines or give supply details.

Listed below are some of the other people who may be involved when requested and when necessary.

Hospital Social Worker

They can explain what services are available and can assess what services need to be put in place at home. They will talk to the patient and you as carer about what the patient needs and wants.

Occupational Therapist

Their aim is to help the patient be as independent as possible in everyday tasks such as bathing, dressing, confidence building and linking to the community. They work closely with the hospital social worker and they can offer support when particular equipment or adaptations are needed.

Physiotherapist

They work with people to help them regain lost movement, improve mobility and to maintain safe independence in such activities as walking and using stairs.

Speech and Language Therapist

They work with adults and children, and can offer information and advice on communication, speech and language and/or eating, drinking and swallowing difficulties.

Dietician

They can offer information and advice to the patient and you, as carer, if a special diet is needed.

Incontinence Advisers

They can offer information and advice about managing bowel and bladder problems. In the first instance you should speak to the community nurse at your Health Centre, who will advise you initially.

Summing Up!

Before leaving hospital the person you care for and, with their permission, you as the carer should receive a copy of the discharge plan. A copy should also be sent to the patient's GP. This should contain the information outlined above. Use the Checklist below to make sure you have all the information you need.

Checklist - Asking Questions

This section provides a checklist summarising key questions to ask yourself before the person you care for leaves hospital. Where you don't have an answer it identifies the person or people you can ask to get an answer!

- **Do I and/or the person I am caring for have a copy of the discharge plan?**

If not, speak to the named nurse or if the hospital social worker is already involved ask to see them.

- **Does the person I am caring for and, with their permission, do I, as their carer, have information about:**
 - medication
 - medical condition
 - future appointments
 - primary health care contacts?

If not, speak to the named nurse.

- **Does the person I am caring for and, with their permission, do I, as their carer, have information on the services they will receive on leaving hospital?**

If not, speak to the named nurse or hospital social worker.

- **The person you care for may have to pay towards the services provided. Has this been discussed?**

If not, speak to the hospital social worker about a financial assessment. Your local Carers Centre or Citizens Advice Bureau (CAB) can also offer support.

- **Can I get a Carer's Assessment?**

Speak to the hospital social worker.

After Leaving Hospital – Services in Your Community

As outlined in section 1, the person you care for and you, as their carer, should be involved in the planning of services and support. To be involved you need to know what services may be available.

This section provides you with basic information about those services, and who provides them. It is divided into 3 main areas – Community Care, Primary Health Care and Voluntary Sector services.

Community Care

The key to receiving Community Care services is a Community Care Assessment, also known as a Single Shared Assessment. This can be carried out by a variety of people including a Social Worker, an Occupational Therapist, Community Nurse or a Housing Support Officer. If the assessment is carried out in hospital, it will form a central part of the discharge plan.

The assessment looks at what support is required to allow the person to live as independently as possible at home. Here are some of the services that can be provided.

- help with meals
- day care services
- respite/short breaks
- help with personal care such as bathing and dressing
- residential and supported accommodation
- help with shopping
- sitter services/care attendants
- equipment, adaptations, transport

This list is not exhaustive but provides a starting point for you, and the person you care for, to think about what you might want and need. There may be charges for these services (see Section 3 for details)

Free Personal Care and Home Care

If the person you care for is 65 or over they will be entitled to free personal care. This includes help with, for example, washing and bathing, and getting in and out of bed. Following discharge they will also be entitled to a maximum of 28 days free home care if they have been assessed as needing home care. Ask about these as part of the assessment.

Who's Who in Community Care

Now you know what services can be provided through Community Care, the next step is knowing who does what. The key people involved are listed below. They can be contacted through your local Social Work office – see Section 5 to find out more about how to contact Social Work.

Social Worker

They will usually carry out the Community Care Assessment (Single Shared Assessment), and will talk to the person you care for about their needs. They should also involve you as the carer. However the assessment will focus on the needs of the person you care for rather than your needs. Your needs as a carer can be assessed through a Carer's Assessment (see Section 4 for details)

When the assessment is carried out as part of a discharge plan it will generally be carried out by a Social Worker based at the hospital. This Social Worker will normally monitor the services provided for up to 4 weeks after leaving hospital. After this time, responsibility for monitoring is handed over to the local Social Work Centre. You should contact them if the situation at home changes and you need further advice and support.

Home Care (Home Helps/Social Care Worker)

They can offer support with cooking, shopping and personal care.

Occupational Therapist

Their aim is to help the patient be as independent as possible in everyday tasks such as bathing, dressing, confidence building and linking to the community. They can advise you about equipment and adaptations. They can also carry out Community Care Assessments (Single Shared Assessments)

Mental Health Officers

They are Social Workers with particular experience and training in the area of mental health. They have statutory responsibilities under the Mental Health (Scotland) Act 1984.

Primary Health Care

General Practitioners (GPs), district nurses, health visitors and practice nurses work together as members of the primary health care team to provide services for people in the community. They work closely with others such as social workers, occupational therapists and physiotherapists, who all offer home visits.

Again it is useful to know who they all are so below is a brief summary of their different roles.

GP (General Practitioner)

They will provide ongoing medical care and advice when the person has been discharged from hospital. They will receive information from the hospital consultant and nursing staff about the medical needs of the person you care for; this should include a copy of the discharge plan. With the permission of the patient they will be able to answer any questions you have on medical matters following the discharge process. They can refer you back to the hospital consultant if required, as well as refer you to the other services you may need.

Community Nursing Team

The community nursing team includes district nurses, health visitors and practice nurses. Community nurses are qualified nurses with specialist knowledge in community health. The **district nursing** service aims to provide 24 hour cover, and provides a wide range of support for patients and carers through all stages of illness such as injections and changing dressings. You can contact them directly if needed. **Practice nurses** provide care in the GP surgery or health centre such as injections and diabetes care. **Health visitors** provide advice and information on a whole range of health-related issues. They can visit you at home and are able to refer people to other services such as social work and occupational therapists.

CPN (Community Psychiatric Nurse)

They are trained to work with people with mental health problems. Offering support to the patient and their families and carers, they can generally be accessed via the GP.

Pharmacist

As with the hospital-based pharmacist, they can offer you advice on your medicines. They can offer all kinds of information such as what to do if a dose is missed, what potential side effects might arise from particular medication, how to help the person you care for to take their medication if they have swallowing difficulties. They will be able to check if the medicines you are prescribed are safe to take with any you may purchase for the person you are caring for. They can also advise on aids to help you remember when the medicines should be taken.

Voluntary Sector

The voluntary sector is a term used to refer to the wide range of services provided by voluntary or charitable organisations. Some of the services that the person you care for receives through Community Care will be provided by the voluntary sector. Here are some examples of services offered by the sector.

- information and advice
- support groups
- sitter and respite services
- day care
- specialist support/information on particular conditions
- counselling
- advocacy
- training on being a carer
- lunch clubs

Some services provided by the voluntary sector are free others are not. You will find more information on these services in Sections 4 and 5. Carers Centres are often the best starting point. They can offer you advice and information and sign-post you to the most appropriate services available to meet your needs.

Finances – Costs and Benefits

There may be financial costs for the services received by the person you care for but they may also qualify for financial help and benefits.

Who will pay?

As well as working out what services the person is entitled to through a Community Care Assessment (Single Shared Assessment), it is also necessary to calculate how much they will pay towards these services.

This will be done through a financial assessment, where the finances of the person you care for will be assessed. This includes any income such as pensions, benefits and savings. Amounts are taken off to cover the person's living costs and then it is determined how much they have to contribute towards the costs of the services provided.

The person you care for can choose *not* to have a financial assessment and in this case they will be expected to pay the full charges of the services provided. Working out how much someone will pay can be complicated.

If you need advice or someone to explain the process to you then contact your local Carers Centre, Citizens Advice Bureau (CAB) or your Social Worker.

Benefits and Financial Support

Both you and the person you are caring for may be entitled to claim benefits.

1. Benefits for the Person You Care For

Below is a brief summary of some of the benefits the person you care for may be entitled to claim.

Disability Living Allowance (DLA)

A tax free benefit for people under 65 who need help with personal care and/or getting around.

Attendance Allowance (AA)

A tax-free benefit for people aged 65 and over who need help with personal care or supervision as a result of illness or disability.

Constant Attendance Allowance

Extra money paid in addition to a war pension or pension for a disability or illness caused by an accident or disease at work.

Incapacity Benefit

Introduced to replace Invalidity and Sickness Benefit and is payable to people who are unable to work and cannot receive Statutory Sick Pay.

2. Benefits for You as a Carer

The only benefit aimed specifically at carers is **Carers Allowance (formerly ICA)**. It can be claimed by carers if you:

- are aged over 16 years
- spend a minimum of 35 hours a week caring for someone
- do not earn more than £77 per week
- are not in full time education
- care for someone who is in receipt of DLA (middle or higher rate) or AA or Constant Attendance Allowance.

However you will not be paid Carers Allowance as well as a retirement pension or Incapacity Benefit. You will be paid whichever is highest. As a carer you may also be entitled to Income Support and a reduction in your Council Tax. This is not an exhaustive list of benefits available. It may seem complicated but there is help.

Checklist – Asking Questions

- Am I clear about what benefits I and the person I am caring for are entitled to claim?**

If not, speak to your social worker, local Carers Centre, or to the Disablement Income Group on 0131 555 2811.

Being a Carer – Support for You

When you become a carer or your caring situation changes, you may find that your life changes in all sorts of ways. You may have to spend more and more time supporting the person you care for. You may have to give up work. You may have to learn to do new things like cooking or dealing with finances. You may have to change the way you view your life.

What are my rights as a carer?

The most important right you have as a carer is to be listened to and to have your views taken into account. This means:

- you should be consulted about the services that could be provided for the person you care for
- you should be asked if you are able and willing to provide care for that person.

If you are providing a lot of care for the person you care for then you are entitled to a Carer's Assessment. Under the Community Care and Health (Scotland) Act 2002 you, as a carer, are seen as a partner in providing care, and you are entitled to this assessment whether or not the person you care for has an assessment.

Carer's Assessment

The Carer's Assessment will look at:

- how caring affects your life
- the things you like doing but perhaps have had to give up as a carer
- what your needs are and if they can be better met by providing extra services for the person you care for

What practical help is there for me?

1. Carers Organisations

There are various carer organisations. Some cover local areas others are city or nationwide. They can offer a range of services which are relevant to you as a carer. For example they can:

- provide information and advice
- offer services such as advocacy, befriending and counselling
- offer relevant training and learning activities (see below)
- put you in contact with other carers
- put you in contact with other local support projects

Further information is included in Section 5. Your local Carers Centre can provide further details.

2. Learning Activities

There are various courses and activities for carers to become involved in, including:

- courses which cover different issues around caring such as handling medication, claiming benefits and dealing with stress
- computer training courses
- arts and crafts, creative writing and local history

Again there is further information in Section 5. Your local Carers Centre can also provide more details.

3. Helplines

Carersline is a helpline specifically run for carers. It is a national helpline and run by Carers UK. Tel: 0808 808 7777. They will provide general information for you as a carer. Carers Scotland also produce a range of leaflets which are free to carers. You can get copies from Carers Scotland on 0141 221 9141.

4. Advocacy

Being heard and having your views taken into account is your most important right as a carer. But getting your thoughts together and communicating them clearly can sometimes be difficult, particularly at times when you are facing lots of change, both practically and emotionally, in your life.

Advocacy services can support you to:

- think through what you want and need to know
- find out who you should be talking to and how to contact them
- say what you think and feel, either by supporting you to speak up for yourself or by providing an advocate who can raise issues for you

5. Getting A Break

Breaks from caring are often referred to as 'respite'. They may last a few hours, a few days or even a few weeks. Some of the different ways you can receive a break from caring are described below.

Home-based Services (Sitter Services) involve someone coming to your home to support the person you care for while you are out. This kind of service usually covers a few hours but can be overnight and may cover several days.

Day Care Services are available at Day Centres or Day Hospitals depending on a person's illness or disability. Often transport is available and trained staff are on hand all day to care for people.

Residential Care can take the form of the person you care for going into hospital, residential homes or a nursing home while you have a longer break.

Hospital-based respite can be arranged through your GP. The other types of breaks can be organised through Social Work. As with the other services mentioned in this folder there may be costs involved in using 'respite' services.

What if I need someone to talk to?

As well as practical support you may find that you need to be able to talk to someone about how you feel. Again support is available.

1. Carers Counselling

Family and friends can provide a lot of support but there are times when you may need some time and space of your own, or time to talk about your feelings with someone not directly involved. Talking to a Counsellor can help.

2. Carer Support Groups

Carer Support Groups are groups of carers who have come together to offer mutual support. It can be helpful to meet other people who understand how demanding it is to be a carer. Support groups offer somewhere to talk, laugh, relax and have a break.

How do I get this practical and emotional support?

For information on all of the support outlined in this section your first stop should be your local Carers Centre. As previously mentioned they can listen to what you need and direct you to the most appropriate services.

The next section 'Where Now? – Useful Contacts' will also provide you with more information on where to go next.

Where Now? – Useful Contacts

The list of contacts below is not exhaustive but will provide you with a starting point. These organisations can link you to other services and support in your area. Unless otherwise stated the organisations are available within office hours.

Carers Centres and Carer Organisations

The following organisations cover **local authority areas**:

The CA(I)RE Project

Provides free adult education courses and support for carers
Eric Liddell Centre, 15 Morningside Road, Edinburgh EH10 4DP
Tel: 0131 446 3317

Carers of East Lothian - Princess Royal Trust Carers Centre
149 North High Street, Musselburgh EH21 6AN
Tel: 0131 665 0135

Carers of West Lothian - Princess Royal Trust Carers Centre
Strathbrock Partnership Centre, 189a West Main Street,
Broxburn EH52 5LH
Tel: 01506 771750

Edinburgh Carers Council
For carers of people who use mental health services
356 Leith Walk, Edinburgh EH6 5BR
Tel: 0131 554 5153

Edinburgh Young Carers Project
For young people and children who are carers in Edinburgh
Norton Park, 57 Albion Road, Edinburgh EH7 5QY
Tel: 0131 475 2322

MECOPP - Minority Ethnic Carers of Older People Project
For carers from the South Asian, Chinese, African and
Afro-Caribbean communities in Edinburgh and the Lothians
23 Leith Walk, Edinburgh EH6 8LN
Tel: 0131 467 2994

Midlothian Young Carers Project

For young people and children who are carers in Midlothian

4 Lothian Street, Dalkeith EH22 1DS

Tel: 0131 654 9540

VOCAL Princess Royal Trust Carers Centre

Provides information and training for carers in Edinburgh and

Midlothian, and a Lothian wide advocacy and counselling service

8 Johnston Terrace, Edinburgh EH1 2PW

Tel: 0131 622 6666

Carers in Midlothian can contact VOCAL Midlothian directly on

0131 663 6869

The following organisations cover **local areas**:

Care for Carers - Provides services for carers living in the

North East of Edinburgh

Lochend House, 33/35 Lochend Road South, Edinburgh EH7 6BF

Tel: 0131 661 2077

Greater Pilton Carers Resource - Provides services for carers
living in the Greater Pilton area

36 Muirhouse Crescent, Edinburgh EH4 4QL

Tel: 0131 315 3130

Oxgangs Pentlands Carers Project - Provides services for
carers living in the Oxgangs Pentlands area

35 Oxgangs Crescent, Edinburgh EH13 9HJ

Tel: 0131 441 5099

Carer Support Service, Queensferry Care in the Community

Project - Provides services for carers living in Queensferry,

almeny, Kirkliston, Newbridge, Ratho Station and Ratho

'The Haven', 25B Burgess Road, South Queensferry EH30 9JA

Tel: 0131 331 5570

Wester Hailes Carers Project - Provides services for carers

living in Wester Hailes

40 Drumbryden Drive, Edinburgh EH14 2QR

Tel: 0131 458 3080

Social Work

City of Edinburgh Council Social Work Services - the Council employs 2 Carer Support and Development Workers covering the North and South of Edinburgh
Shrubhill House, 7 Shrub Place, Edinburgh EH7 4PD
Tel: 0131 553 8452/3

East Lothian Council Social Work and Housing, 9-11 Lodge Street, Haddington EH41 3DX
Tel: 01620 826600

Midlothian Council Social Services, Fairfield House, 8 Lothian Road, Dalkeith EH22 3ZH
Tel: 0131 270 7500

West Lothian Council Social Work Department, West Lothian House, Almondvale Boulevard, Livingston EH54 6QG
Tel: 01506 777000

Other Useful Contacts

Lothian Health Council
Provides information on all aspects of the NHS services including support in making complaints against the NHS
21 Torphichen Street, Edinburgh EH3 8HX
Tel: 0131 229 6605

Citizens Advice Bureau (CAB)
To find out where your nearest CAB is look in your phone book or call 0131 550 1000 for details

The Interpretation and Translation Service (ITS)
Can provide an interpretation and translation service free of charge to all patients. If an interpreter is needed contact:
Central Library, George IV Bridge, Edinburgh EH1 1EG
Tel: 0131 242 8181

SNIP (Special Needs Information Point)

Different legislation applies to children and different services are available. SNIP can provide further information on for example entitlement to leave for parent carers, and accessing financial support. Royal Hospital for Sick Children, 14 Rillbank Terrace, Edinburgh EH9 1LN
Tel: 0131 536 0583

Helplines

Below are the contact numbers of some more Helplines. Again this list does not include all of the Helplines available but provides you with a starting point.

Alzheimers Scotland - Action on Dementia Helpline (24 hours)
Provides information and advice for people affected by dementia
Tel: 0800 317817

Macmillan CancerLine
Available between 9 am and 6 pm Mon - Friday
Provides information and emotional support for people living with cancer
Tel: 08088 080000

Chest, Heart and Stroke Advice Line
Available 9.30 am to 12.30 pm and 1.30 pm to 4 pm Mon - Friday
Provides information and advice for people affected by heart disease and strokes
Tel: 0845 077 6000

NHS Helpline
Available between 8 am and 10 pm every day - provides information about the services available in your area
Tel: 0800 224488

Saneline
Available between midday and 2 am every day - provides information and advice for people affected by mental health issues
Tel: 0845 7678000

Checklist – Asking Questions

Here again are the key questions to ask yourself before the person you care for leaves hospital, together with the person to ask if you do not have an answer.

- **Do I and/or the person I am caring for have a copy of the discharge plan?**

If not, speak to the named nurse or if the hospital social worker is already involved ask to see them.

- **Does the person I am caring for and, with their permission, do I, as their carer, have information about:**
 - medication
 - medical condition
 - future appointments
 - primary health care contacts?

If not, speak to the named nurse.

- **Does the person I am caring for and, with their permission, do I, as their carer, have information on the services they will receive on leaving hospital?**

If not, speak to named nurse or hospital social worker.

- **The person you care for may have to pay towards the services provided. Has this been discussed?**

If not, speak to the hospital social worker about a financial assessment. Your local Carers Centre or CAB can also offer support.

- **Am I clear about what benefits I and the person I am caring for are entitled to claim?**

If not, speak to your social worker, your local Carers Centre or to the Disablement Income Group on 0131 555 2811.

- **Can I get a Carer's Assessment?**

Speak to the hospital social worker.

- **Do I know what services and support are available to me as a carer?**

If not, contact your local Carers Centre.

AND FINALLY!

Keep asking questions, ask until you get the answers and information you need to help you with your caring responsibilities.

If you have other questions or if you are having difficulty in getting answers to the above questions then please do not hesitate to contact:

VOCAL (Voice of Carers Across Lothian)

Carers Centre

8 Johnston Terrace

Edinburgh EH1 2PW

Tel: 0131 622 6666

What do you think?

Every effort has been made to make sure that 'Home from Hospital' is clear, accurate and relevant to carers. However information changes and this pack will be updated each year.

Your feedback and comments on the areas below will be very useful in the production of future editions of the pack. Please help by completing and returning this brief feedback sheet to VOCAL using the address given over the page - no stamp is needed!

1. How easy did you find it to understand the information in 'Home from Hospital'? (Please circle the appropriate statement)

Very easy

Quite easy

Quite hard

Very hard

2. Did you find the information you needed? (Please circle the appropriate statement)

Very easily

Quite easily

Not at all

3. Were there any areas not covered which you would have liked information about? (Please comment in the space below)

4. Is there information which needs to be updated eg. contact details? (Please use the space below)

5. Do you have any other comments?

Name, address and telephone number (you do not have to give this information. Any information you do provide will be treated in the strictest confidence)

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Thank you for taking the time to provide feedback - it is greatly appreciated!

**Please send your feedback to VOCAL,
Freepost SCO7064, Edinburgh EH1 0BR**