
Support at home

*A guide to services
in the community*

Patient Information



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Introduction

You may be about to go home from hospital or be attending regularly as an outpatient. In either case help and support are available when you are at home, both from the hospital and from services in the community.

This booklet gives details of these services, who provides them and how they are organised. If you have any concerns or questions about your care at home, please contact your GP (General Practitioner or family doctor) who can refer you to the appropriate community services. However, if you are already in contact with community services, please contact the relevant service directly.

If you have any concerns about your medical condition, please contact your GP, unless you have been asked by medical staff to make direct contact with the hospital.

Services provided by the hospital

When you are an inpatient

When you are an inpatient, you may be concerned about how you will cope when you go home. Circumstances can change and you may need help which you did not need before.

During your stay, the ward nurses will ask you how you have been managing at home and discuss with you what help is available when you leave. If you plan to stay with relatives or friends when you leave hospital, please tell the ward nurses as soon as possible. You will need to register with a local GP on a temporary basis in order to get prescriptions or use community nursing services.

The nurse caring for you can arrange for a referral to be made to nursing services you may need at home such as district nurses or other community specialist nurses. You may be referred to the community or hospital Clinical Nurse Specialist (CNS), discharge coordinator and other members of the multidisciplinary team such as a dietitian, physiotherapist or occupational therapist. They can also help plan your discharge with you and your carers, and arrange other services if needed. If you need social services, such as help



with personal care or meals on wheels the ward nurses can arrange a referral to your local authority social services department.

When you are ready to go home, your hospital doctor will:

- Prescribe a two week supply of any medicines you need. Check that you understand the instructions on the container(s). You will be given two copies of your discharge prescription, one for you and one to hand to your GP.
- Arrange with community professionals for the supply of any medical equipment you might need, for example, oxygen cylinders.
- Write to your GP with details of your hospital treatment and progress.

Attending as an outpatient

While attending the hospital as an outpatient, you may also need the help of community services. The clinic nurses can arrange nursing care at home, such as district nurses or other specialist nurses. They can also refer you to the CNS, discharge coordinators and other members of the multidisciplinary team. If you need help from social services, the outpatient staff will be able to advise on how you can refer yourself to your local authority.

Your hospital doctor will prescribe your medicines and write to your GP about your treatment and progress.

Rehabilitation and supportive services

Throughout your care at The Royal Marsden, you are likely to come into contact with many different professionals who are part of the multidisciplinary team. They work together to plan the best care and treatment for you. Their help can be very important when planning the support services you may need at home.

You may already have met some of the following team members during the time you have been visiting the hospital. However, if you have not and you think they may be able to help you, ask your doctor or nurse when you are next at the hospital.

Additional information about these team members and other services can be found in the booklet *Your guide to support, practical help and complementary therapies*, available at the Help Centre.

The multidisciplinary team may include the following professionals:

Clinical nurse specialists have experience of working in particular areas of cancer care such as breast care, lymphoedema, psychological care, stoma care and symptom control. They can offer you advice and help, and can refer you to local community specialist nurses.


Discharge co-ordinators work closely with other members of the multidisciplinary team and community services, including social services and community healthcare colleagues. They organise the care and support you may need when you are going home from hospital. This may include NHS continuing healthcare funding, a social services package of care. The discharge co-ordinators can also provide general information about community services.

Dietitians provide advice about diet before, during and after treatment. They can also suggest ways of overcoming eating difficulties and how to use nutritional supplements, if appropriate. The dietitian prescribes initial supplies of supplements and/or special feeds. You will need to contact your GP for future prescriptions.

Occupational therapists can offer advice on how to manage everyday activities at home safely and in a way which helps you remain independent. They may suggest equipment or adaptations to the home to help with daily living activities and strategies to manage tiredness and breathlessness.

Occupational therapists in the hospital setting teach relaxation techniques and ways of reducing anxiety. These techniques can be used at home.

Home visits to carry out an assessment of your needs may be possible if you live near the hospital. If this is not possible, arrangements will be made for a community-based occupational therapist to visit your home.



Physiotherapists provide advice on any problems to do with movement, such as exercises to increase muscle strength or the range of joint movement. Treatment can be given as an outpatient or inpatient. Physiotherapists can help you if you have difficulty moving around. They can advise on walking aids to use at home and may teach you new ways of doing certain activities. The physiotherapy staff will work with you and your carers to help you adjust to any problems you are experiencing. They can also arrange follow-up care in the community where appropriate.

Social workers are experienced in working with people who have to adjust to changes or experience difficulties in their lives. This may include patients, and their partner, family or carer. Depending on where you live, you may have an assessment from your own local authority social worker or care manager, or the hospital may provide information to support the care you need for going home and the local authority may reassess once you are at home.

Any member of the multidisciplinary team can discuss the help you may need to be discharged home safely. If you need any services provided at home, depending on your need, social services can be arranged for your discharge from hospital.

The Welfare Rights Advisor can give you information and advice on benefits and income maximisation, and signpost you to further advice services for employment, housing, immigration and debt management.

Speech and language therapists help patients with communication or swallowing problems. Treatment can be given as an inpatient or outpatient. If appropriate, patients can be referred to local speech and language therapy services.

Services provided in the community

There are various organisations which can provide services, help and support in the community, although these vary from area to area. Some services need a professional referral, from a doctor or nurse. Others can be contacted directly by the public. Your GP surgery or health centre can give you the appropriate numbers.

GP (family doctor)

During your treatment for cancer, your GP is responsible for your medical care when you are at home. You will get prescriptions for your medicines and some other items from your doctor, who will usually ask for 48 hours notice for repeat prescriptions. As well as checking your symptoms and finding out how your treatment is progressing, other help can be arranged through the surgery if you have difficulty managing at home.

These services include:

- admission to hospital or a hospice
- ambulances/transport
- counselling
- nursing services
- oxygen at home.

GPs provide a 24 hour service with out-of-hours cover at night and weekends. However, in an emergency dial 999. The ambulance will take you to the nearest accident and emergency department. On arrival, tell the doctors or nurses that you are being treated at The Royal Marsden and what your treatment involves. This will help the staff to provide you with the right care and they will also be able to contact your doctor at The Royal Marsden.

If you have been given specific instructions to contact The Royal Marsden or if you experience a particular symptom, please phone the number you have been given (see page 14).

Community nursing services

District nurses are trained to assess nursing needs and plan care at home. This includes practical nursing, such as dressing wounds and giving injections, making sure medicines are taken safely and giving advice about bowel problems or other symptoms. They may also be able to arrange for equipment to be provided at home, such as commodes or pressure-relieving mattresses.



Health visitors can give support and advice to families with young children.

Practice nurses are based in GP surgeries or health centres. They carry out general treatments such as dressings and giving injections in the surgery. Practice nurses often run clinics and they can also put you in touch with other community services.

Private nursing services can be arranged instead of or as well as NHS nursing services. Nursing agencies can provide qualified nurses or carers to carry out a variety of duties. This service has to be arranged and paid for by the patient or carer. Private insurance plans may provide some funding towards nursing care at home and it is important to check this before arrangements are made.

School nurses can help support a child or teenager if a member of the family has cancer.

Intermediate care

It is recognised that people are best cared for at home if possible. To help you cope when you first go home from hospital, intermediate care teams may provide a period of intensive care or rehabilitation following your hospital stay. The occupational therapist and/or physiotherapist in the hospital can discuss this with you.

Nursing and residential homes

If you can no longer manage at home, you may need to be cared for in a nursing or residential home. You may be assessed either while you are in hospital or when you are at home. This could include an assessment for NHS continuing healthcare funding.

NHS continuing healthcare funding

Patients who have complex healthcare needs in the community and require assistance with personal care may be entitled to NHS continuing healthcare funding. To apply for this, an application may be made by the hospital, the district nurse, GP or community palliative care nurse.

Community palliative care services

Community palliative care teams may be based in a hospice or other community setting. Specialist palliative care nurses (who may be Macmillan nurses) work closely with a consultant in palliative medicine and other healthcare professionals in the palliative care team. They provide advice and information about treatments, side effects, pain control and other symptoms. They also offer emotional support to patients and their families.

Marie Curie nurses are arranged by the district nurse or Macmillan nurse. They can provide nursing care for an occasional night or part of the day. The service is limited and can only be provided to people who are very ill.

Hospices and palliative care units provide inpatient care and support for people during their illness. Many different people work together within hospices and palliative care units to provide physical and spiritual care, pain relief and control of symptoms. Emotional help for families and carers is also available. Staff may also be able to provide advice about benefits and other financial help, such as special grants.

The team may include:

- doctors
- nurses
- physiotherapists
- occupational therapists
- social workers
- complementary therapists
- pastoral care.

Services may include:

- Inpatient care for a time to relieve symptoms or to give the patient or carer a short break (respite care) or for palliative care.

- Day care at a centre which may offer art or music therapy, relaxation or other complementary therapies. There is also the opportunity to see a doctor.
- Home care by specialist nurses (see page 6) and other team members to help patients remain comfortably at home for as long as they wish.

Local authority social services

Social workers/care managers can assess what services are needed by patients and carers at home, and provide emotional support or counselling.

Social services may provide the following services, however they may vary depending on your local authority:

- home care, such as help with personal care, meal preparation or housework
- some day care services
- meal services
- advice about welfare benefits and housing problems
- assessment together with nursing services for care home placements
- practical help with the care of children or dependent relatives
- information for people with disabilities, such as blue badge, freedom pass or taxi card
- community occupational therapists who can assess daily living needs and provide equipment (see page 7).

You can contact social services yourself by telephone or you can ask your GP or district nurse to refer you.

Local pharmacy (chemist)

The local pharmacist is a valuable contact and can provide information about medicines. The pharmacist may also offer a

delivery service for repeat prescriptions and a dosette box for managing your medicines.

Voluntary organisations

There are many organisations which offer advice, support and services but the availability of these may differ from area to area.

Services may include:

- information and advice, including financial and legal
- transport to and from hospital
- care attendant schemes, support for carers, 'sitting', 'good neighbour' or holiday schemes
- equipment hire
- counselling or bereavement support
- support or self-help groups which may provide telephone help lines, information, group meetings, hospital or home visiting and complementary therapies.

Contact The Royal Marsden Help Centre (see page 12) for information about groups or services in your area. Information may also be displayed in your GP surgery or local library.

General information

Access to your hospital medical records

The doctors, and other staff caring for you, are always willing to discuss your illness and treatment and to answer any questions.

You have the right to see medical records made about you. This may include data held on computer and manual systems. If you would like to see this information, you will need to send a written request, called a Subject Access Request, to the health records manager.

Further details about how you can access your medical records can be found in the booklet *Your guide to The Royal Marsden*. This can be found at the Help Centre.



Confidentiality and medical information

We ask you for information about yourself so that you can receive proper care and treatment. Information concerning you and your illness may be shared with other professionals involved in your care. If you are receiving care from other organisations as well as the NHS, we may also need to share some information about you with them. While we collect your information because it is necessary for your health care and treatment, we may need to use it for other reasons. The main ways in which we use your information are:

- giving you health care and treatment
- helping us manage and plan services within the hospital to meet patient needs in the future
- helping staff to review the care they provide to make sure it is of the highest standard
- training and educating staff
- research approved by the Local Research Ethics Committee
- looking after the health of the general public
- managing and planning the NHS.

We only ever use or pass on information about you if there is a genuine need for it. Whenever we can, we remove details that identify you. The sharing of some types of sensitive personal information is strictly controlled by law.

With your permission, the doctors will usually keep your next of kin informed. Your family doctor will also be kept informed of your progress.

Further details about how we use your information can be found in the leaflet *Your health information, your confidentiality*. This can be found at the Help Centre.

If at any time you would like to know more about how we use your information, you can speak to staff in the Help Centre on 020 7811 8438.

Consent

You have a choice when to agree to any form of examination, treatment or care. You are always free to say no, or to ask for more information before you make up your mind. It is important that your consent is genuine or valid and this means:

- you must be able to give your consent
- you must be given enough information to enable you to make a decision
- you must be acting under your own free will and not under the influence of another person.

In order to make a decision, you need to have information from health professionals about the treatment or investigation which is being offered to you. Please ask questions if you do not understand or if you would like more information.

If the person asking for your consent to the treatment is not able to answer your questions, please ask them to find out or arrange for someone else to talk to you about your concerns.

Help us to help you

Please let us know if you change your name, address, telephone number or family doctor.

If you cannot keep an appointment, please call us as soon as possible on: Chelsea: 020 7808 2431
Sutton: 020 8661 3430

We welcome your feedback which helps us to improve our services in a safe and supportive environment that is free of prejudice, harassment and violence, meeting the needs of all who pass through our doors. The Royal Marsden prides itself in being socially and culturally inclusive and sensitive to the needs of the patients and carers it serves. All staff who provide care do so in an atmosphere of respect, non-judgement and empowerment.



Information

If at any time during your stay in hospital you have any questions, please do not hesitate to ask the ward nurse or a member of your medical team. Alternatively, you can contact The Royal Marsden Help Centre. It may help to write down your questions so that you do not forget them.

The Royal Marsden Help Centre

The Help Centre provides information, support and advice to people with cancer, their families and friends, and staff involved in their care. The staff work closely with other staff at The Royal Marsden and have links with local hospitals and community-based organisations. In Chelsea, the Centre is in the Chelsea Wing opposite the Medical Day Unit on the ground floor. In Sutton, the Centre is to the left of the main entrance. You can call in during opening hours, which are displayed outside the Centres. Staff are available to guide you through the information and to offer you any advice and support you may need.

You can also contact the Help Centre by:

Telephone: 020 7811 8438

Email: patientcentre@rmh.nhs.uk

Patient Information Service

The impact of a diagnosis of cancer can have an effect on you, your family and friends, and raise all kinds of questions. As well as information about cancer itself, you will be able to find information about the practical help and support available when living with cancer. Finding the right information and support can help you and your family to cope in a better way.

Information is available about cancer, its treatment, effects and side effects. This can be found in different forms including leaflets, booklets, books and a limited selection of audio visual aids.

You may also like to visit our website at www.royalmarsden.nhs.uk which has an online Patient Information library.

Patient Advice and Liaison Service (PALS)

We like to know when we are doing things well but more importantly we need to be told when things go wrong, so that we can put them right. If you wish to make a comment about the service or care you have received in the hospital, please speak to the relevant service manager, such as the sister/charge nurse or head of department.

PALS can also help with any individual issues or concerns that are raised. Suggestions made may be incorporated into Trust policies.

You may prefer to raise your general issue or concern in writing. Viewpoint comment cards are available in all patient areas for you to so.

If you are still unhappy then it may be helpful to speak to the staff in PALS who will listen to your concerns and liaise on your behalf to try and resolve issues. They can also give you information and guidance on making a complaint.

If you wish to complain in writing, please write to:

Email: patientcentre@rmh.nhs.uk

Or

PALS Advisor

The Royal Marsden Help Centre

The Royal Marsden NHS Foundation Trust

Fulham Road

London

SW3 6JJ



The Royal Marsden Macmillan Hotline: 020 8915 6899

You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

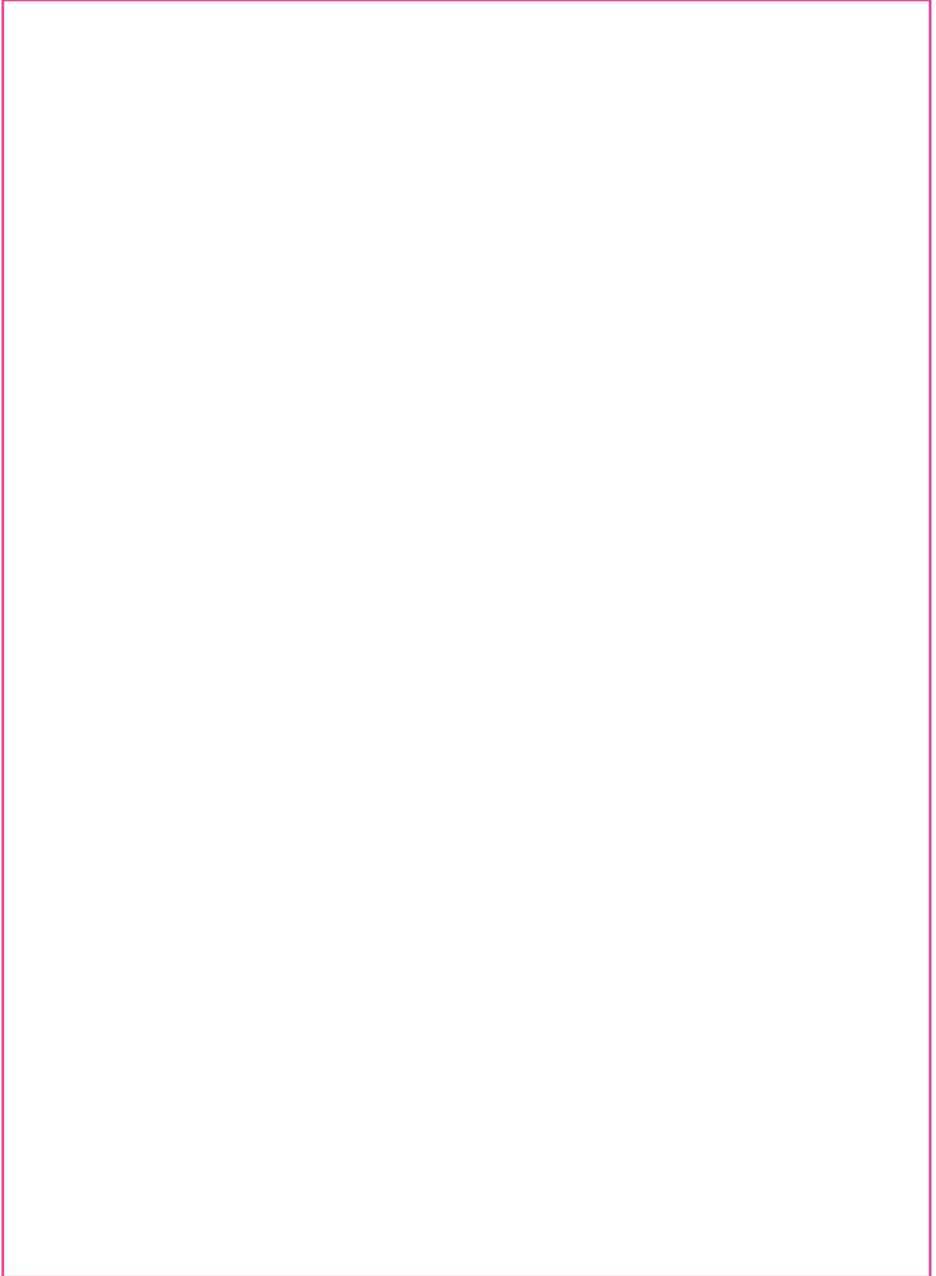
This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

Should you require information in an alternative format please contact The Royal Marsden Help Centre.

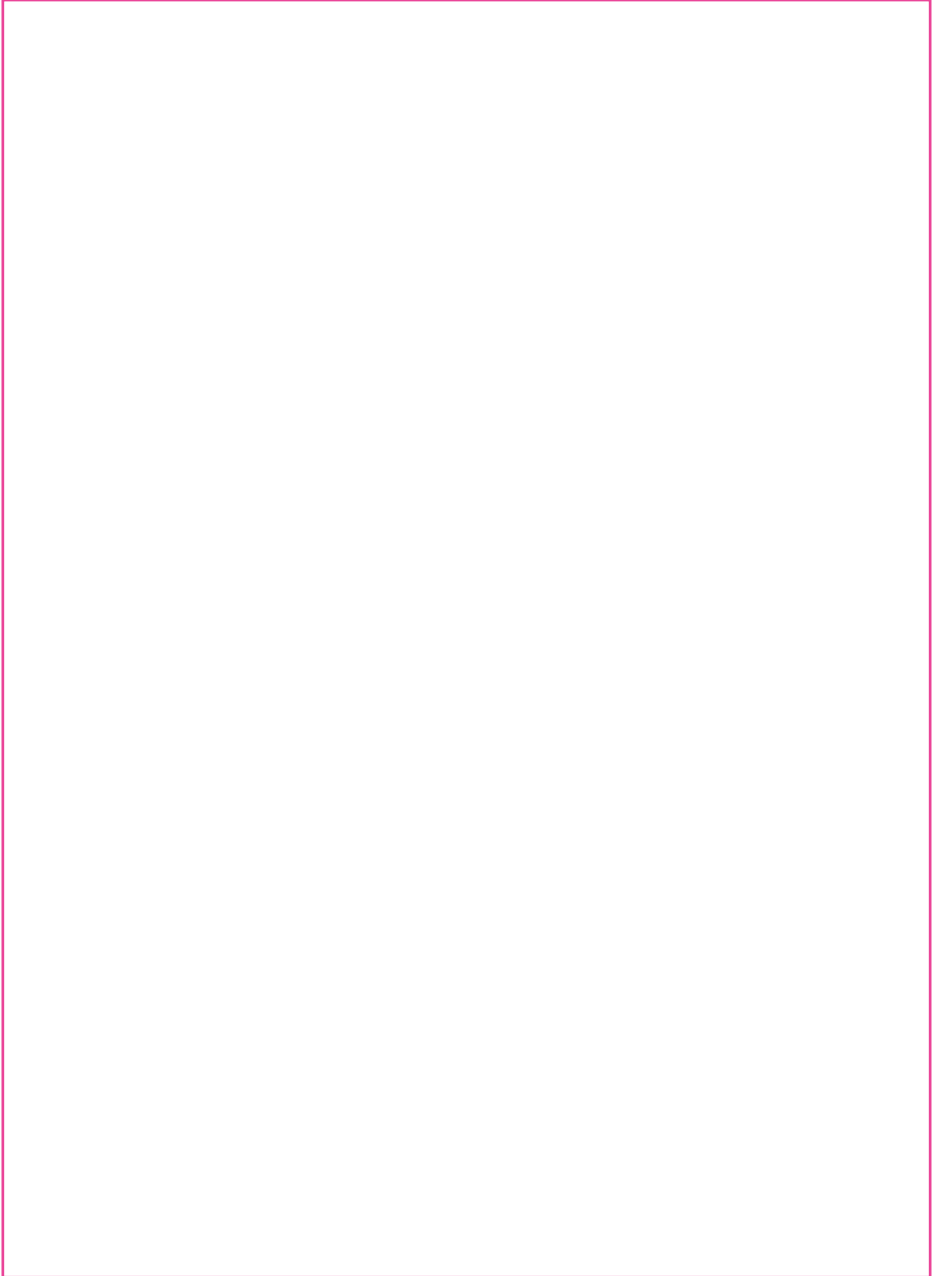
Contact details

Your doctor, keyworker, nurse specialist or other staff may fill in their contact details here.

Notes and questions

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This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from: The Royal Marsden Help Centre
Freephone: 0800 783 7176
Email: patientcentre@rmh.nhs.uk

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royalmarsden.org
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The Royal Marsden publishes a number of booklets and leaflets about cancer care. Here is a list of information available to you.



Diagnosis

- A beginner's guide to the BRCA1 and BRCA2 genes
- CT scan
- MRI scan
- Ultrasound scan
- Lynch Syndrome



Treatment

- Central venous access devices
- Chemotherapy
- Clinical trials
- Radiotherapy
- Radionuclide therapy
- Your operation and anaesthetic



Supportive care

- Eating well when you have cancer
- Lymphoedema
- Reducing the risk of healthcare associated infection
- Support at home
- Your guide to support, practical help and complementary therapies



Your hospital experience

- Help Centre for PALS and patient information
- How to raise a concern or make a complaint
- Making your stay with us safe
- Your health information, your confidentiality



Please visit www.royalmarsden.nhs.uk/patientinformation where several patient information booklets are available to download.



Radiotherapy and
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