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1. Introduction

Marie Curie Hospice is a registered provider of palliative care. It was established to provide specialist palliative and end of life care for people with advanced progressive illnesses and to give support to families caring for loved ones both in hospice and at home. It is a place where everything we do is centred on patients, families and carers. Our team will provide specialist palliative care and advice that supports you.

Most people who use the Hospice usually spend up to 2 weeks with us in the in-patient unit, allowing the hospice team enough time to ensure your care and treatment promotes maximum comfort and well being. During your admission as an in-patient we will listen, discuss and plan your care with you, respecting your choice and dignity. You and your family will be kept informed about all aspects of your care and in return we invite you to inform us of any comments you have which will help us to continually improve the quality of our service.

The majority of patients referred to Marie Curie, may access our services from our Day Therapy and community Marie Curie Nursing services. The aim of these services is to support and promote quality of life whilst at home. These vital services can often make the difference between a patient being able to remain at home or being admitted to hospital.

Palliative care is defined by National Council for Palliative Care (NCPC) as the active care of patients with advanced, progressive illness. Management of pain and other symptoms, and provision of psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Marie Curie Services currently provide specialist palliative care of the type defined by the NCPC, delivered and supported by means of the following services:

- In-patient facilities at Marie Curie Hospice, Belfast
- Day Hospice in Belfast, Newtownards and Downpatrick
- Marie Curie Nursing Service in the community including 24 hour nursing care. Our services are available across Northern Ireland and referrals are accepted from District Nurses, General Practitioners and Specialist Nurses
- Rapid Response services works in partnership with GP Out Of Hours in the Southern and Northern Trusts
- A full range of medical and allied health professional services including physiotherapists, occupational therapists etc
- Family support, spiritual and bereavement care to families and friends of Marie Curie Hospice patients
- Comprehensive training and education programmes.

Our staff have appropriate qualifications and expertise in palliative care. Their aim is to provide the best quality of life for their patients and patients’ families, focusing not only on physical care but also on the need for emotional, social and spiritual support. We tailor our services to the individual needs of each patient and family.

There is no charge for hospice care; it is available on the basis of need. We also provide advice to health and social care professionals.
I hope you find this Patient Guide and the accompanying service information leaflets informative, should you require any other information on services please do not hesitate to speak with a member of staff or visit our website to access information on our services including published quality and patient feedback reports – www.mariecurie.org.uk.

My team and I look forward to welcoming you, your family and friends to the Marie Curie Services in Northern Ireland.

Heather Weir  MSc BSc (Hons)  Dip RN
Divisional General Manager (NI)
2. **Respecting patients’ rights**

- Marie Curie Caring Services will respect and respond to your need for dignity, privacy and spiritual support at all times.
- Respect and respond to your religious and cultural beliefs will be respected and responded to at all times.
- You will be involved in decisions regarding your care and will be given clear explanations of your condition and treatment, investigation or procedure proposed, including risks and alternatives prior to receiving treatment.
- Support your expressed preference for future care and treatment options will be respected including your right to register an advance directive to refuse emergency resuscitation. We will as much as practicably possible, respect your wish to die in a place of your own choosing.
- You may express your feelings and emotions about your approaching death in your own time and in your own way.
- Should you require any help to exercise your rights, you should speak with a member of the clinical team who will support you with your choices.

3. **What you can expect from our staff and volunteers**

- To have those caring for you to be professional, sensitive, skilled, caring and honest.
- You and your carers and visitors will be treated with courtesy and respect at all times by hospice staff and volunteers.
- To have things explained to you tactfully, with sensitivity and in terms you can understand.
- To have the right to be referred to a health professional you consider acceptable and to seek a second opinion if you wish. To request this you should speak with a member of the nursing or medical team at any time.
- Marie Curie Caring Services will endeavour to respect your preference for being cared for/treated by female/male members of staff, however this will be within the constraints of the service and may not always be possible.
- To ensure your care and treatment plan is tailored to meet your holistic needs and promote your comfort.
- To act as your advocate should this be necessary.
- To ensure that you will not be left to die alone unless you so request.
- To investigate areas of concern you, your relatives or carers may have about your care.
- To ensure that your choice to partake or not in clinical staff training is respected.
- To ensure that your choice to give or refuse valid consent to take part in research is respected.

4. **Providing information**

You, or your designated next of kin where appropriate, have the right to:

- Expect that your confidentiality with all aspects of your care including your health record is respected by all hospice staff and volunteers.
- Expect all staff who meet you face to face to wear name badges.
• Have any proposed treatment, including any consequences and alternatives, clearly explained to you before you decide whether to agree to it.

• Have access to your health records, and to know that everyone working for the Marie Curie Caring Service is under a legal duty to keep your records confidential. It should be noted that at times it may be necessary to share information with other agencies involved in your care, however you have the right to object to the use and disclosure to other agencies of confidential information that identifies you.

• Refuse to have your health record used for the purposes of clinical audit and quality improvement, this can be done by letting the nurse or doctor caring for you know that you refuse.

• Have any complaint about your care speedily and thoroughly investigated and to receive a written reply from the Marie Curie Caring Services within agreed timescales.

• Be confident that your complaint will not be recorded in your medical notes and will not affect your future care in any way.

• Support in contacting the Regulation and Quality Improvement Authority if necessary. We will ensure that an member of the management team will assist you to do this at your request.

• Give consent to take part in research or training or to withdraw at any time. You should discuss this with the nurse or doctor caring for you during the course of your stay with us.

5. **Information on accommodation**

The adult hospice is a specialist unit with 18 beds, comprising of 16 en suite rooms and one two bedded room en suite, all set in homely and relaxed surroundings. Patients have access to a central courtyard and gardens. We always try to promote privacy and dignity. Patients are allocated to rooms on basis of need and where possible, choice.

6. **Engaging with people who access our services**

We welcome and value your comments and feedback, and would invite you to talk with staff, complete comment cards, use the ipads to give us realtime feedback on your experience of care or become an Expert Voice to help us continually improve our services.

We publish our patient and family feedback on our website and throughout our services.

7. **Management of complaints and concerns**

• Marie Curie Caring Services aims to provide all our patients carers and families with a quality service. In most instances we succeed, but occasionally things can go wrong and people may wish to complain about the service provided.

• A Patient Information leaflet entitled “Tell us what you think?” has been developed and is available in all departments to inform patients and the public how to raise a complaint.

• Any person wishing to make a complaint/concern will be treated with dignity, courtesy and respect and given appropriate information on how to make the complaint.

• Complaints can be made either verbally, in writing or through a third party.

• All complaints will be treated confidentially.

• If you are an in-patient the best person to talk to is the nurse in charge of the ward. If you are an outpatient, please ask a member of staff at reception who you should talk to.
When we receive a written complaint we will write back to you within two working days to confirm we have received your letter.

We will always do our best to give you a full reply as quickly as possible. We aim to give a complete reply within 20 working days from the receipt of your complaint.

If a delay occurs we will still write to you within 20 working days to update you on how the matter is progressing.

Resolution at local level must be attempted in all cases of complaint.

At any stage, a meeting can be arranged with you or your named representative to discuss any concerns. A home visit can be arranged as necessary.

All complaints will be thoroughly investigated, with agreement on the issues that should be investigated.

If you are not happy with the response you receive you can make a complaint in writing to the Chief Executive:

Dr Jane Collins
Chief Executive
Marie Curie Cancer Care
7th Floor, 89 Albert Embankment
London SE1 7TP

If complainants are not satisfied with the response from Marie Curie Cancer Care to their complaint, they can write to the Northern Ireland Ombudsman, 33 Wellington Place, Belfast, BT1 6HN.

Independent Reviews are conducted by a convenor and a panel, and they will investigate the complaint and respond to the complainant within a set timescale.

A full copy of the Complaints Policy is available on request.

8. How to contact the regulation and quality improvement authority

Regulation and Quality Improvement Authority
9th Floor Riverside Tower
5 Lanyon Place
BELFAST
BT1 3BT

Telephone (028) 9051 7500
Fax (028) 9051 7501

9. How to access regulation and quality improvement authority inspection reports and other quality improvement surveys

Patients and members of the public can access Regulation and Quality Improvement Authority inspection reports of the Marie Curie Caring Services by contacting the Divisional General Manager (NI), who can be contacted at:

Marie Curie Hospice
1a Kensington Road
Belfast
BT5 6NF
Marie Curie Services are committed to providing quality services and undertakes a programme of clinical audit to measure its services against standards of care. To access our clinical audit annual report, patients and members of the public should contact the Divisional General Manager. Alternatively you can visit the Regulation and Quality Improvement Authority website and download the latest inspection report.

10. How to access the Patient Guide and other information

The patient guide is easily accessed by patients and public. A full copy can be located in the in patient unit, reception or by asking any member of our staff. This patient guide supplements individual services information booklets. It is also available on our website (www.mariecurie.org.uk) with other service information including patient feedback surveys and quality reports.

11. Additional Information on Marie Curie Services

Dependant on which service you have been referred to you will receive an information booklet containing useful information on our services, these include information on how to get to the hospice, what to bring on admission, information on what to expect when you arrive, accommodation, smoking, telephone access, visiting times, meals, the hospice team, going home, how to make comments on our services and how to make a donation.

We are committed to making patients and families feel comfortable and safe whilst receiving excellent care in our hospice and are happy to discuss any aspect of our service. For additional information on other organisational policies please contact a member of staff who will be happy to help.

Whilst continuing to provide high quality services and information to the public, we would welcome and invite you to make comments on this guide or any other information that is published by Marie Curie.

From time to time we like to consult with patients and family members/carers when new or revised information materials are being prepared, this will be done in a sensitive and professional manner by key individual members of staff.

Marie Curie Hospices are here for people with serious illnesses and their families. Whether someone comes in to stay or visits regularly, we give them the excellent care they expect – and the best quality of life they could wish for.

mariecurie.org.uk

Charity reg no. 207994 (England & Wales), SC038731 (Scotland)