

**Draft**  
**National**  
**Care**  
**Standards**  
**for Hospice Care**  
*A Consultation Paper*



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*December 2001*



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## INTRODUCTION

### The Scottish Commission for the Regulation of Care

From 1 April 2002, the Scottish Commission for the Regulation of Care (the Care Commission) will take over responsibilities for the registration and inspection of voluntary hospices in Scotland. This was previously the responsibility of local health boards.

### Voluntary Hospices in Scotland

There are 14 hospices in Scotland which are run by voluntary organisations and which are therefore part of the independent healthcare sector and subject to regulation by the Care Commission. The hospices have charitable status and make no charge to the users of their services. They all receive part of their running costs from the NHS and all work in close partnership with local NHS services.

Of the 14 hospices in Scotland at present, 13 care for adults and one cares for children and young people up to the age of 21. A second children's hospice is planned. The national care standards for hospice care will apply to all hospices. They include a small number of additional standards which are specific to the children's hospices only and which are indicated in italics in the text. The children's standards are addressed to the child's parents or guardians.

### Palliative Care

Hospices provide *palliative care* for people with cancer and other chronic, progressive conditions. Palliative care aims to maintain and, as far as possible, improve the quality of life for people faced with a progressive illness, such as cancer. Palliative care is concerned with:

- controlling pain and other distressing symptoms;
- helping patients and families cope with the emotional upset and practical problems of the situation;
- helping people to deal with spiritual questions which may arise from their illness;
- helping people to live as actively as possible despite their illness; and
- supporting families and friends in their bereavement.

### Hospice services

Most hospices provide a mix of in-patient care, day care and home care although they do not all provide all three types of service. Patients are referred to the hospice by their GP or hospital doctor for whichever sort of care is best suited to their needs at the time. Some people might receive home care, day care and in-patient care over the course of their illness and others might receive only a short period of hospice care to manage their symptoms or help with other problems arising from their illness. These days hospices are not just places where people go to die. A significant proportion of people admitted to a hospice are able to go home after a short stay.

Hospice care is provided by a multi-professional team who have undergone specialist palliative care training. Hospices which have a full team of appropriately qualified doctors, nurses and other health care professionals are recognised as providing *specialist palliative care* for those patients and families with complex needs.

## Link to the Clinical Standards Board for Scotland (CSBS)

The Clinical Standards Board for Scotland (CSBS) has developed clinical standards for specialist palliative care which will apply to voluntary hospices and to the NHS. The voluntary hospices are required by the Care Commission to participate in the accreditation process of the CSBS. The CSBS standards cover clinical components of care which are not addressed in detail in these standards. In addition, the CSBS generic standards relating to patient focus and safe clinical care have been incorporated into the national care standards for hospice care.

## The national care standards

Scottish Ministers set up the National Care Standards Committee (NCSC) to develop national care standards. The NCSC carried out this work with the help of a number of working groups. These groups included people who use the services, their families and carers, along with staff, professional associations, regulators from health and social care, local authorities, health independent providers and many others. Many others were involved in the consultation process.

As a result, the standards have been developed from the point of view of the person who uses the service. They describe what each individual person can expect from the service provider. They focus on the quality of life that the person using the service actually experiences.

## Using the national care standards

If you are thinking about using the services of a hospice, you may want to refer to the standards to help you decide. If you are already using the service, you may use the standards when discussing the service you receive with the staff and managers of the service, people involved in referring you to the service, or someone acting on your behalf.

Standards make it clear that everything about the service is focused on the quality of life you experience as a result of receiving that service. If things go wrong, you can refer to standards when you raise concerns or make a complaint. (See “expressing your views”, standard 7)

## The principles behind the standards

The standards are based on a set of principles. The principles themselves are not care standards but reflect the recognised rights which you enjoy as a citizen. These principles are the result of all the contributions made by the NCSC, its working groups and everyone else who has contributed to the standards as they were being written. They recognise that services must be accessible and suitable for everyone who needs them. They reflect a widespread agreement that the experience of the people using the services is very important and should be positive. It should help you keep and increase your independence and take an active role in deciding what contributes to your quality of life.

## The main principles

The principles are dignity, privacy, choice, safety, realising potential and equality and diversity.

### *Dignity*

Your right to:

- be treated with dignity and respect at all times; and
- enjoy a full range of social relationships.

### *Privacy*

Your right to:

- have your privacy and property respected; and
- be free from intrusion as long as it is safe for you and every one else.

### *Choice*

Your right to:

- make informed choices, while recognising the right of other people to do the same; and
- know about the range of choices.

### *Safety*

Your right to:

- feel safe and secure in all aspects of life, including health and well-being;
- be secure in the knowledge that adults have responsibility for children's safety;
- enjoy safety but not be over-protected; and
- be protected from exploitation and abuse.

### *Realising Potential*

Your right to have the opportunity to:

- attain and achieve all you can in accordance with your talents;
- make full use of the resources available to you; and
- make the most of your life.

### *Equality and Diversity*

Your right to:

- live an independent life, rich in purpose, meaning and personal fulfilment;
- be valued for your ethnic background, language, culture and faith;
- be treated equally and to live in an environment which is free from bullying and harrassment; and
- be able to complain effectively without fear of victimisation.

## **The Scottish Commission for the Regulation of Care**

The Regulation of Care (Scotland) Act 2001 (the Act) set up the Scottish Commission for the Regulation of Care (the Care Commission). The Care Commission will register and inspect all the services to be regulated against the national care standards issued by Scottish Ministers. The Care Commission will have its headquarters in Dundee, with regional offices across the country. It will assess applications from people who want to provide registered services. It will inspect the services to make sure that they are meeting the standards and the regulations.



## The Scottish Social Services Council

The Scottish Social Services Council (the Council) was established on 1 October 2001 under the Act. It will also have its headquarters in Dundee. The Council will have the duty of promoting high standards of conduct and practice among social services workers, and in their education and training. To deliver its overall aims of protecting service users and carers and securing the confidence of the public in social services, the Council has been given four main tasks. These are: to establish registers of key groups of social services staff; to publish codes of practice for all social services staff and their employers; to regulate the training and education of the workforce; to undertake the functions of the National Training Organisation for Personal Social Services.

## How standards and regulations work together

The Act gives Scottish Ministers the power to publish standards which the Care Commission must take into account when making its decisions. It also gives Scottish Ministers the power to make regulations imposing requirements in relation to care services.

The standards will be taken into account by the Care Commission in making any decision about applications for registration (including varying or removing a condition that may have been imposed on the registration of the service). All providers must provide a statement of function and purpose when they apply to register their service. On the basis of that statement, the Care Commission will determine which standards will apply to the services the provider is offering.

The standards will be used to monitor the quality of care services and their compliance with the Act and the regulations. If, at inspection, or at other times, for example, as a result of the Care Commission looking into a complaint, there are concerns about the service, the Care Commission will take the standards into account in any decision on whether to take enforcement action and what action to take.

If the standards were not being fully met, the Care Commission would note this on the inspection report and require the service manager to address this. The Care Commission could impose an additional condition on the service's registration if the provider persistently, substantially or seriously failed to meet the standards or breaches a regulation. If the provider does not then meet the condition, the Care Commission could issue an improvement notice detailing the required improvement to be made and the time scale this needs to be achieved in. Alternatively, the Care Commission could move straight to an improvement notice. The Care Commission would move to cancel the registration of any service if the improvement notice does not achieve the desired result. In extreme cases (i.e. where there is serious risk to a person's life, health or well-being) the Care Commission could take immediate steps to cancel the registration of any service without issuing an improvement notice.

Regulations are mandatory. In some cases not meeting a regulation will be an offence. This means a provider may be subject to prosecution. Not meeting or breaching any regulation is a serious matter.

Decisions by the Commission on what to do when the standards or regulations are not met will take into account all the relevant circumstances and be proportionate.

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# PREAMBLE

## Background

Hospices are currently registered and inspected by their local health board, according to the Nursing Homes (Scotland) Act 1938. In the past, this has created some difficulties, because the nature of hospice provision is very different to that of nursing homes. Scottish hospices have therefore welcomed the opportunity created by the new regulatory system for them to be registered and inspected against a set of standards developed specifically for hospice services, as part of the independent healthcare sector.

The NCSC Palliative Care Working Group (Annex A) which drafted the standards was given the remit to follow the format and style of the other NCSC standards for care homes and other services, and to address them to the user of the hospice service. The standards are therefore drafted from the point of view of what the hospice user should be able to expect. The Working Group has considered what evidence could be sought by the Care Commission to demonstrate that a hospice meets the standards and this work is being passed to a separate Inspection Methodology Group of the NCSC.

At the same time as developing these NCSC standards, Scottish hospices have also been involved in a joint project between the Scottish Partnership Agency for Palliative and Cancer Care and the Clinical Standards Board for Scotland to develop clinical standards for specialist palliative care which will be applicable across voluntary and NHS services. The hospices were anxious to avoid a situation where they would be required to work to two different sets of standards. Following discussions between the CSBS and the NCSC, it was agreed that hospices should be required to meet the generic standards of the CSBS. These generic standards have therefore been incorporated in the attached standards for hospices and will be monitored by the Care Commission. Hospices will also be expected to participate in the accreditation process of the CSBS for specialist palliative care which will be monitored by CSBS peer review every three years.

The Palliative Care Working Group was given a very short timescale to complete its work and has met five times between June and September 2001. Comments and suggested improvements to the standards will be very welcome.

## 2. Before using the service

### 2.1 INFORMING AND DECIDING

#### Quality of Life

You can make a positive and informed decision about using the hospice services, helped by the quality and accuracy of the information you receive.

#### You can expect that:

#### You are given accurate and clear information about the hospice's services.

1. Local hospitals and GPs receive information from the hospice about its services and its criteria for referral so that they can help you to come to a decision.
2. You receive clear, understandable and appropriate information written in plain English or in a language and format that is suitable for you. It should include:
  - details of the aims and philosophy of the hospice;
  - criteria for admission to hospice in-patient, home-care and day-care services;
  - details of the services provided by the hospice;
  - contact names and telephone numbers;
  - details of the hospice comments, suggestions and complaints policy;
  - practical arrangements for admission, transport and visiting;
  - details of the hospice resuscitation policy; and
  - your responsibilities towards the hospice.
3. You have the opportunity, if you are well enough and wish to do so, to visit the hospice in advance.
4. You have access to the hospice policy on advance directives.
5. You have access to the services in the hospice, based on your identified healthcare needs and as far as possible your individual preferences.
6. Your access to hospice services is not compromised by physical, language, cultural or other barriers.

## 2.2 ASSESSING YOUR NEEDS

### Quality of Life

You receive services that respond to your needs and preferences.

#### **You can expect that:**

#### **You are involved in decisions about your own care, through effective two-way communication and information sharing.**

1. You receive an initial assessment by the most appropriate member of the multi-professional team to help determine what care you need and prefer.
2. You receive information on the care proposed for you, what results are expected and your expected length of stay. With your consent, members of your family, or your carers, will also receive this information.
3. There will be a full multi-professional assessment of your physical, social, psychological, spiritual and intellectual needs.
4. Before your care plan is agreed, staff will explain your condition clearly to you and will also explain any treatment, investigation or procedure proposed, including the risks and alternatives, so that you can give your informed consent.
5. You are involved as a partner in making decisions about your care. Your family or carers will also be involved in decisions, as appropriate.
6. The hospice keeps an accurate, up-to-date record on all aspects of your care which is readily available to any clinician involved in your care.

## 2.3 GUIDELINES AND LEGISLATION

### Quality of Life

You are confident that your legal and human rights will be protected and that the service is managed in line with all applicable legal requirements.

#### You can expect that:

**All aspects of your care will be delivered within the law and according to best practice guidelines, where they exist.**

1. Your safety will be maintained by staff who are complying with all relevant legislation and best practice guidelines.
2. There will be up-to-date documentation regarding the hospice's policies and procedures for all relevant legislation and best practice guidelines which will include:
  - fire, including evacuation procedures
  - security, including the protection of vulnerable adults
  - health and safety, including manual handling
  - environmental health, including food safety
3. Your human rights and privacy will be preserved and any information you give to any employee of the hospice will remain confidential, unless there is a lawful basis for disclosure of information.
4. You have access to your own health records, which will be kept confidentially and securely.

## 2.4 PREMISES

### Quality of Life

You feel safe and comfortable in the hospice and confident that your right to privacy is protected.

#### You can expect that:

**You will be cared for in an environment that is safe, comfortable, allows your care to be delivered effectively and safely and protects your right to privacy and confidentiality.**

1. The hospice will be accessible to you and those important to you. This includes:
  - accessible by public transport<sup>1</sup>;
  - accessible in a wheelchair;
  - suitable car parking; and
  - easy to find your way around.
2. You and those important to you can easily contact members of staff when required by a telecommunications system appropriate to the size of the establishment and a paging system and nurse call system.
3. The environment will be suitable for the delivery of the social, psychological and spiritual care you require. This will include:
  - all rooms that you use will be well maintained and there will be good use of lighting, decor and furnishings;
  - where your health and the needs of other patients permit, you will have the choice of whether you wish to be cared for in a single room or a room with multiple beds in it;
  - there will be an area where you and your visitors can be welcomed to the hospice and can wait in comfort for an appointment if necessary; and
  - you will have the key to a lockable storage space.
4. The environment will be suitable for the delivery of the physical care you require. There will be:
  - adequate and suitable accommodation for the range of care and treatment that is delivered by the hospice. This includes:
    - invasive procedures
    - physiotherapy
    - occupational therapy
    - out patient consultations
    - day care

<sup>1</sup> Applies to new hospices only

- adequate smoking and non-smoking lounges;
- enough electric sockets to support all equipment required;
- arrangements in place to ensure an uninterrupted electrical supply;
- toilets that you can get to easily from all patient areas;
- a range of baths and showers to allow you to bath/shower independently if you wish and are able, or to be assisted to bath or shower if and when required;
- enough single rooms to allow you to be isolated if your condition requires it; and
- bed spaces and single rooms of an adequate size to house all equipment required.

### 3. Having confidence in your care

#### 3.1 QUALITY OF CARE

Quality of Life

The hospice provides you with high quality care.

**You can expect that:**

**You will receive safe and effective care and treatment based on available up to date evidence.**

1. You will be told the names and job titles of the key healthcare professionals responsible for managing your care and how to contact them.
2. Your care will be planned and delivered in accordance with up to date evidence-based clinical guidelines and other current best clinical practice.
3. Staff will review their clinical practice through an ongoing process of multi-professional audit against relevant protocols, guidelines and good practice statements.
4. The safety of work practice and the working environment is ensured by a process of risk management.
5. The hospice provides clinical care which reflects the participation and achievement of satisfactory reports in the Clinical Standards Board for Scotland (CSBS) accreditation programme for its specialist palliative care standards.



## 3.2 STAFF<sup>2</sup>

### Quality of Life

Your care will be provided by a multi-professional team who are suitably qualified and skilled for the job and will have been employed fairly and treated well at work.

#### You can expect that:

**The staff caring for you will have the correct qualifications and experience for the job they are required to undertake. They will have been selected through professional selection and recruitment procedures. They will be treated well while at work and given the necessary equipment and facilities to do their job.**

1. All recruitment and selection to the hospice will follow a clearly written recruitment and selection policy.
2. There will be regular performance management and every member of staff will have a personal professional development plan which will reflect the recommendations of professional and regulatory bodies.
3. There will be adequate facilities for the staff who care for you and support your care. This includes facilities for:
  - catering
  - laundry
  - cleaning
  - adequate space for multi-professional staff meetings
  - facilities which allow staff to have meals and breaks away from patients and families
4. The hospice has an education and training strategy, including induction training, in place which meets the needs of staff and the services they provide.
5. All healthcare professional staff have essential qualifications, as laid down by regulatory bodies. They have the essential competencies required for the services and procedures they provide.
6. The hospice checks the qualifications of all staff and all necessary records before they start work.
7. The hospice identifies and meets staff training needs for communication skills.
8. The hospice promotes and monitors effective teamwork across all disciplines and with staff in other organisations.
9. All healthcare professional staff demonstrate responsibility and accountability for their own professional practice.
10. The hospice has mechanisms in place to assist staff to raise, in confidence, concerns over any aspect of service delivery they feel may be having a detrimental effect on your care and the care of others, or the quality of service.

<sup>2</sup> The definition of staff includes paid employees and appropriately trained volunteers.

11. The hospice keeps a confidential record of all staff concerns and of the action taken in response.
12. The hospice enables staff to have access to occupational health, including counselling support, on a confidential basis, as and when required.
13. *Where sick children are cared for, a minimum of one RSCN will be on duty at all times. Adequate RSCN's will be deployed to reflect the nursing needs of the children staying in the hospice.*

### 3.3 INFECTION CONTROL

#### Quality of Life

You are protected from contracting preventable infections while in the hospice and if you are admitted with an infection you receive appropriate care.

#### **You can expect that:**

**You will be cared for by staff who are trained and competent in minimising the risk of cross-infection and follow an infection control policy.**

1. Staff will be educated about the infection control policy, taking account of their grade, role and responsibility. The policy will be written with input from a bacteriologist and an infection control specialist, based on practice which has been shown to be most effective and comply with Clinical Negligence and Other Risks Indemnity Scheme (CNORIS) guidelines.
2. Staff will take appropriate steps to prevent you from acquiring preventable infection.
3. If you have an infection, the hospice may take appropriate steps to protect other patients and staff from acquiring your infection.
4. You will, whenever possible, be fully involved with, and understand the need for infection control procedures and policies.
5. Staff will treat you with dignity if you have an infection and take account of your wishes in planning the most appropriate care for you as an individual.

### 3.4 MEDICINES MANAGEMENT

#### Quality of Life

Medication forms a significant part of controlling your symptoms. The hospice will manage your medication during your stay and at the time of discharge to maximise the benefit and minimise harm.

#### You can expect that:

1. You will have the correct medicines, administered safely, in time and in good condition. This means that;
  - any medicines you bring into the hospice will be stored safely and used, if necessary, only for your treatment;
  - prescribed medicines will be available at all times;
  - all medicines will be stored securely and in appropriate conditions;
  - all equipment for medicines administration to be used safely.
  - you can make informed choices about your medication;
  - any specialist treatment will be provided by staff with specialist training; and
  - any medicines you bring into the hospice and do not require at discharge will be safely disposed of, with your permission.
2. When you are discharged from the hospice, you will be able to continue to take your medicines safely.
  - you will be given an appropriate supply of your current medications at the time of discharge. This will normally be a seven-day supply;
  - you will have been given a written and verbal explanation of the medications you are to take. This information can be given to a carer if you prefer;
  - you, or your carer, will be familiar with any equipment you will need to take your prescribed medicines;
  - you will have in place any equipment you need to take the prescribed medicines;
  - procedures will be in place to make sure that you can obtain any specialist medicines you need from your local pharmacy;
  - any special needs relating to dispensing of your medicines are formally assessed;
  - you will be supplied medicines in such a way that you can easily and safely take them; and
  - any special needs relating to the dispensing of your medicines have been arranged with your local pharmacy.

### 3.5 EQUIPMENT FOR THERAPEUTIC AND MONITORING PURPOSES

Quality of Life

The equipment required to support your care is available.

**You can expect that:**

**There will be appropriate procurement, provision, maintenance, repair and use of equipment<sup>3</sup> suitable for patients with palliative care needs.**

1. Your equipment needs will be assessed as an ongoing and integral part of your care.
2. Equipment required for your care in the hospice will be available to you and can be used for you by staff and those important to you, when appropriate.
3. Staff are aware of equipment available to you and them to assist with your care and rehabilitation.
4. All staff using and prescribing equipment for your care will have the appropriate training.
5. All equipment used in your care will be maintained as part of a planned maintenance programme.
6. All equipment will be used safely.
7. Any equipment needed for your discharge will be identified and arranged as early as possible in your care.

### 3.6 CARE OF CHILDREN

Quality of Life

*As a parent or carer of a sick child, you can be sure that your child's rights will be respected and protected.*

***You can expect that:***

1. *Staff will demonstrate gentle methods of care and management in their day to day contact with children.*
2. *Information will be available appropriate to your child's needs and stage of development.*
3. *Staff will promote the rights of your child, being sensitive to the signs of possible neglect or abuse, ensuring any concerns are quickly dealt with.*

<sup>3</sup> In the following standards the word 'equipment' is used to encompass all rehabilitation, monitoring and treatment devices.

## 4. Getting the most out of life

### 4.1 LIVING WITH ILLNESS

Quality of Life

The hospice aims to support you in your illness and to help you to continue to get the most out of life.

**You can expect that:**

**You will receive encouragement, help and support to enable you to achieve your full potential, maintain your independence for as long as possible, and adapt to your changing condition.**

1. Your care plan is focussed on rehabilitation.
2. You are made aware of any financial, social and legal supports available to you.
3. A realistic set of goals, responsive to changes in your condition, is negotiated for your care.
4. Multi-professional support enables you to live as actively as possible.

### 4.2 WELL-BEING

Quality of Life

You feel respected as an individual and that all your needs are recognised.

**You can expect that:**

**You will be treated with respect and will be supported and assisted as you explore physical, psychological, social, spiritual and intellectual areas of need.**

1. You experience respect as a person, with respect to your ethnicity, gender, sexual orientation, faith, age, intellect, disability.
2. You will be assisted in prioritising areas of distress for attention, if this is what you want.
3. You will have your physical symptoms actively managed according to best current practice, while being made aware of any treatments or services which may help you to cope better.
4. You will be able to spend time with staff exploring any issues of concern to you.
5. You will be supported by staff as you attempt to adjust to your condition and find some sense of meaning in your experience.
6. You can continue to practice any religious framework which you find comforting.

### 4.3 PERSONAL LIFE

Quality of Life	You achieve the right balance for you between privacy and companionship
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**You can expect that:**

**You will be able to continue to experience periods of solitude while sharing time with those who are important to you.**

1. You have periods of solitude if that is your choice.
2. You have the reassurance of companionship when that is important to you.
3. You are enabled to continue to feel part of your family group.
4. You are able to receive visitors in privacy.
5. You are enabled to continue with hobbies and interests whenever possible.

### 4.4 DAILY LIFE

Quality of Life	You feel at ease in the hospice environment.
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**You can expect that:**

**You will feel comfortable and at ease in your care environment with the pattern of your daily care routine reflecting your chosen lifestyle.**

1. You have your choices reflected in your care routine.
2. You have your needs discussed, along with those of your family and carers, and others within your care environment.

### 4.5 PLAY, EDUCATION AND LEISURE

Quality of Life	<i>Play, education and leisure are recognised as being a vital part of a child's daily life.</i>
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***You can expect that:***

1. *Staff have a range of communication skills appropriate for children of all ages and ability.*
2. *Your child's play and leisure needs will be assessed, in order to maximise independence, ability and enjoyment, and this to form an integral part of the care plan.*
3. *Staff will liaise with your child's nursery, school, or college if appropriate, to aid communication and provide continuity.*
4. *A range of specialist toys, games and play equipment will be available.*
5. *Brothers and sisters can be actively involved in play, and staff will be sensitive to their needs.*

## 4.6 KEEPING IN TOUCH

Quality of Life

You continue to feel part of things.

**You can expect that:**

**You will receive support to maintain ongoing involvement with those people, and organisations, which are important to you.**

1. You have continued contact with those people who are important to you.
2. You enjoy a system of open visiting when your energy and inclination allow.
3. You have a telephone available for your use, if possible in a private area.
4. You are enabled to have visits out when possible.

## 4.7 ENJOYING FOOD

Quality of Life

You enjoy your food

**You can expect that:**

**You will be offered a choice and variety of food, which respects your ethnic, cultural and dietary requirements.**

1. The hospice complies with all current environmental, health and food safety legislation.
2. You are consulted regarding your preferences and choice of food.
3. Your nutritional needs are assessed in line with national guidelines.
4. Menus are planned to offer a balanced choice for each meal.
5. A choice of snacks, drinks and food is available when you wish.
6. If you require gastrostomy or nasogastric feeding, staff are able to carry out any procedures necessary in an informed and sensitive way.
7. Staff are sensitive to any practical help you may require to enjoy your food and drink.

## 4.8 CARING FOR THOSE IMPORTANT TO YOU

### Quality of Life

You are comforted by the knowledge that the hospice will support your family and carers.

#### **You can expect that:**

#### **The needs of those important to you will be identified and met in a sensitive manner.**

1. Your family, friends and carers will be cared for by a multi-professional team.
2. Those involved in caring for you will be given information and support to assist them if desired, while respecting your confidentiality.
3. *Staff will communicate appropriately and sensitively with children, allowing them to express themselves and providing opportunities for play.*

## 4.9 SUPPORT AND CARE OF THE FAMILY

### Quality of Life

*You will be comforted by the knowledge that a children's hospice recognises the special needs of yourselves and the well children in the family.*

#### **You can expect that:**

1. *Accommodation will be available free of charge, enabling you to stay together as a family.*
2. *You can participate as much or as little as you wish in your child's daily care.*
3. *You are central in any decision making processes affecting your child and family.*
4. *Care and support from a multi disciplinary team will help you to adjust to, and live with changes you may be experiencing in your life.*
5. *You are involved in the discussion and planning identifying the needs of the well children in your family.*
6. *You can access complimentary therapies if you wish.*



## 5. Moving on

### 5.1 PLANNING YOUR DISCHARGE

Quality of Life

Your discharge from the hospice will be a smooth transition to continuing care.

**You can expect that:**

**The hospice has comprehensive procedures for planning your discharge in partnership with yourself and others involved.**

1. Your care plan includes planning in advance for your discharge.
2. All relevant information is communicated in good time to you and to any others involved in your continuing care.
3. You are discharged only when follow-up services (including equipment and adaptations where required) have been requested. Staff will record reasons for any delay in your discharge.
4. You receive information on discharge about plans for your continuing care, including your medication.

## 6. Care at the end of life

### 6.1 AROUND THE TIME OF DEATH

#### Quality of Life

As your death approaches, you and those important to you will be helped to come to terms with it and to express your preferences for your care.

#### You can expect that:

**Your wishes are taken into consideration when planning the care you will receive in the last few days and hours of your life and how your body will be treated after your death.**

1. Your preferred place of death is discussed with you and those important to you and every effort is made to achieve it.
2. Your care for your last few days and hours will be discussed with you and, if you wish, with those important to you, and your wishes will be respected, where possible.
3. You will be able to choose whether or not you wish to have someone with you when you die and who that person should be. Every effort will be made to achieve that.
4. There will be facilities available for those important to you to stay with you during your last few days and hours if that is your and their wish.
5. When you die, your body will be treated with dignity, sensitivity and respect and in accordance with your expressed religious, faith or cultural preferences.
6. There will be suitable facilities available for those important to you to spend as much time with you after your death as they require.
7. Those important to you will be offered the support of a bereavement service after your death.

## 7. Expressing your views

### 7.1 ADVOCACY, COMMENTS, CONCERNS AND COMPLAINTS

#### Quality of Life

The hospice welcomes your views on services so that it can continuously improve the quality of its care. If you feel unable to voice them, you will receive support from a representative of your choice.

#### **You can expect that:**

**You and those important to you are encouraged to express any views you may have on any aspect of the hospice service, either personally or through your chosen representative.**

1. You will be supported in a safe and confidential manner to make known any views, whether positive or negative, on any aspect of your care.
2. You will have access to the hospice policy on patient advocacy.
3. You or your representative will have access to easily understood internal and external complaint procedures which include information about who to make complaints to and how to contact the Care Commission.
4. The latest report on the hospice by the Care Commission will be made available if you wish to see it.
5. Your concerns or complaints are dealt with promptly and sympathetically, and full information is provided to you about what happens as a result.
6. Staff will listen to your chosen representative as if the views expressed were your own and will respect any outcomes in the same way.

## Annex A

### PALLIATIVE CARE WORKING GROUP

Mrs Margaret Stevenson (Chair)	Director, Scottish Partnership Agency for Palliative and Cancer Care
Dr Lorraine Briggs	Scottish Executive
Ms Andrea Cail	Head of Care, Rachel House, Children's Hospice
Mrs Margaret Dunbar	Director of Nursing, St Columba's Hospice
Mrs Anne Dunley	Scottish Executive
Ms Gail Holloway	Occupational Therapist, Fairmile Marie Curie Centre
Mr David Johnson	Director, Waverley Care Trust
Ms Trudy Lafferty	Matron, St Vincent's Hospice
Ms Fiona Montgomery	Hospice Pharmacist, Strathcarron Hospice
Dr Alison Morrison	Medical Director and Consultant in Palliative Care, Ardgowan Hospice
Ms Susan Munroe	Centre Director, Hunters Hill Marie Curie Cancer Centre
Dr Linda MacCallum	General Practitioner and MacMillan GP / facilitator in Palliative Care
Mrs Alison Wagstaff	Chaplain, St Columba's Hospice
Mr Jim Wallace	Officer, Royal College of Nursing
Ms Wendy Whyte	Registration & Inspection Officer, Argyll & Clyde Health Board
Lynn Taylor	Scottish Executive