nationalCarestandards short breaks and respite care services for adults

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Introduction

nationalCarestandards short breaks and respite care services for adults

Introduction

Short breaks and respite care – a developing range of services¹

Short breaks and respite care cover a range of services and situations. Different ideas are emerging about the purpose of the break. Evidence of the need for breaks is also moving from a general awareness of their value to much more detailed information that people need breaks in different ways at different times and for different periods. As the carer's voice has become stronger through carers' organisations and centres, attention has been focused on short breaks and respite care. Now, as people who use services are being consulted, a greater emphasis is being placed on the quality of services and the standards that you and your family can expect to receive.

The distinctive feature of respite care is that the break should be a positive experience for you and your carer (if you have one) in order to improve the quality of your life and to support your relationship. It can be provided in your home or elsewhere and may extend from a few hours to a few weeks.

The quality of 'spare bed' respite care currently provided in long-stay care homes has been heavily criticised. The Guidance for the UK Carers Strategy recommends that 'good quality short-term breaks will ensure separate provision is made in units which provide both long-term care and short-term breaks'.

Other short break services depend on how willing people are to open their doors to others. These are services that have to be carefully developed and supported. As new ways and best practice for short breaks are developed, so standards will also change and develop.

Most short break services involve you being temporarily separated from your carer (if you have one). However, support at home and holiday escorts may also allow family members to enjoy the break with you. Breaks may be close to home or farther away. Breaks may be provided by services or through individual arrangements paid for by direct payments.

The particular needs of rural communities where residential facilities tend to be small, few in number and scattered about should also be recognised.

¹ There is a growing debate about the term 'respite care'. Some feel it describes the importance of the break for the carer, and others feel that it is a negative term. For the purpose of these standards, 'short breaks' and 'respite care' have been adopted and used at different points to reflect the terms that are currently used and understood. In both cases, they cover a service that may be provided in the person's own home, in a family home or in a care home.

Short breaks and respite care – a range of settings

Short breaks and respite care can be offered in a wide variety of settings including:

- breaks in respite-only units (specialist guest houses, community flats, purpose-built or adapted houses);
- breaks in care homes;
- breaks in the home of another individual or family who have been specially recruited;
- breaks in your own home through a care attendant or sitting service;
- holiday breaks;
- supported breaks for you and your carer together;
- befriending schemes where volunteers provide short breaks;
- breaks in supported accommodation; and
- flexible breaks through direct payment arrangements.

Also some forms of day care should be seen as falling within the definition of short breaks and respite care. These were covered by the 1996 Guidance on Respite Care. Although it is clearly seen as a service for you, the user, befriending is also included to cover breaks using local leisure resources with a befriending escort.

Short breaks and respite care and the national care standards

All providers must provide a statement of function and purpose when they are applying to register their service. On the basis of this statement, the Scottish Commission for the Regulation of Care ('the Care Commission') will determine which standards will apply to the service that the provider is offering.

The standards for short breaks and respite care will apply to all services where short breaks and respite care are offered. They cover your needs and the needs of your carer or family (or both). They cover some services that rely on volunteers. Some services to you, the user, may incidentally provide your carer with a break. These indirect sources of support are not included within the scope of these standards.

This means that the standards for short breaks and respite care should:

- be applied with reference to other care standards that relate to specific services;
- be applied with due regard to the differences between services;
- help to achieve a balance in which service quality is guaranteed and a range of service models can develop; and
- be read as referring to all services.

The national care standards

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

As a result, the standards have been developed from the point of view of people who use the services. 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.

The standards are grouped under headings which follow the person's journey through the service. These are as follows:

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Before using the service (standards 1 to 6)

- 1 Informing and deciding
- 2 First meetings
- 3 Your legal rights
- 4 Positive experiences
- 5 Management and staffing arrangements
- 6 Individual agreement

Using the service (standards 7 to 18)

- 7 Starting to use the service
- 8 Making choices
- 9 Feeling safe and secure
- 10 Exercising your rights
- 11 Expressing your views
- 12 Lifestyle
- 13 Eating well
- 14 Keeping well healthcare
- 15 Keeping well medication
- 16 Private life
- 17 Daily life
- 18 Supporting communication

Going home or moving on (standard 19)

19 Ending the short break or respite care

Using the national care standards

As a user of the service, you may want to refer to the standards when you, your family, carer or representative are considering a short break or respite care. While on a short break or in respite care, you may use the standards when discussing the service you receive with those providing your care and support, care staff or befriending volunteer or with the service provider.

If things go wrong, you can refer to the standards to help you raise concerns or make a complaint. (See 'Expressing your views', standard 11.) If you have a carer, she or he can refer to the standards to know what support the service provider will give her or him. Providers will use standards to find out what is expected of them in offering support and care services.

The principles behind the standards

The standards are based on a set of principles. The principles themselves are not standards but reflect the recognised rights people enjoy as citizens. These principles are the result of all the contributions made by the NCSC, its working groups and everyone else who responded to the consultations on the standards as they were being written. They recognise that services must be accessible and suitable for everyone who needs them, including people from black and ethnic minority communities. They reflect the strong agreement that your experience of receiving services is very important and should be positive, and that you have rights.

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 unnecessary intrusion.

Choice

Your right to:

- make informed choices, while recognising the rights 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 wellbeing;
- enjoy safety but not be over-protected; and
- be free from exploitation and abuse.

Realising potential

Your right to have the opportunity to:

- achieve all you can;
- make full use of the resources that are 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 be cared for in an environment which is free from bullying, harassment and discrimination; 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 has 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 Act created the Scottish Social Services Council ('the Council') which was established on 1 October 2001. 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; and to undertake the functions of the National Training Organisation for the 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 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).

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.

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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 breached 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 for this. 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 wellbeing) 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 Care Commission on what to do when standards or regulations are not met will take into account all the relevant circumstances and be proportionate.

1-6 Before using the service (standards 1 to 6)

- 1 Informing and deciding
- 2 First meetings
- 3 Your legal rights
- 4 Positive experiences
- 5 Management and staffing arrangements
- 6 Individual agreement

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Before using the service

Introduction to standards 1 to 6

Informing and deciding

A short break or respite care should be a positive experience for you and your carer (if you have one). It improves your quality of life by providing an opportunity to have a break from your usual routine. You make a positive and informed decision about the break, helped by the quality and accuracy of the information you receive.

Most breaks last from a few hours to a few weeks. Some breaks support you if you have more complex needs, with longer planned breaks, or as an introduction to independent living. The pattern of breaks may change to allow for your changing needs. While most breaks are planned, emergency care is sometimes needed, and standards reflect this. This may be the case if the short break relates to family stress or illness rather than long-term disability.

You must have proper information to help you reach a decision. You can expect it to be up to date and reliable, in a format and language that you can easily understand and keep. Information about the services should be backed up by details that give you confidence that the break will meet your support and care needs.

First meetings

Being able to meet a representative of the service, or to visit the accommodation or to have someone visit you, is essential to making a positive choice about using the service. You may sometimes want your family, carer, friends or representatives to be able to be involved in these meetings as part of helping you to decide. You can expect that the people who will be giving you support and care will respect your need to have enough time to make a decision.

Positive experiences

Whatever the nature of your break, you can expect to enjoy a range of positive experiences. For example, if the break is away from your own home it will accommodate you and any equipment you need in a way which supports your right to privacy and dignity. If the break is in a care home with permanent residents, the standards will be carefully applied to make sure that your rights and choices and those of the permanent residents are respected and that the experiences in both cases are positive.

Your wellbeing and safety are most important in whatever environment you are in.

Management and staffing arrangements

You must be confident that the service is managed properly and gives those providing it the support and training they need to provide good quality care, in line with relevant legislation and guidelines.

You must also feel confident that the respite care you receive is tailored to fit your individual needs and those of your carer. An 'individual agreement' records your hopes of the service and your needs, and how the provider will meet these. You can expect that, with your permission, those providing your care and support will know all the relevant aspects of the agreement. You can also expect to be able to discuss your needs with your care manager and service provider beforehand.

Informing and deciding

Standard 1

You have all the information you need, in a format that you can easily understand, to help you decide about taking a short break or using respite care.

- 1 You receive advice and support to make sure that the information reflects your own situation and need.
- 2 Your carer's need for information, advice and support will be respected and responded to.
- 3 You have unbiased information about the possible benefits or disadvantages of a short break or respite service. Your carer's needs are taken into account when considering the possible benefits of the service.
- 4 You and your family, carer or representative can discuss your choice of service with staff from the short breaks and respite care service.
- 5 You have detailed information about the service in a language and format that you can easily understand. The information covers:
 - the aims of the service;
 - the kind of service it provides;
 - the cultural needs it caters for;
 - the basic cost of the service and the likely charge to you;
 - your rights and responsibilities as someone who uses the service;
 - insurance cover for you and your belongings;
 - risk assessment procedures;
 - arrangements that need to be made if the service closes or if there is a change of ownership; and
 - the complaints procedure and how to use it.

- 6 Where the short break and respite service includes an overnight stay away from your own home, your information includes:
 - living arrangements and lifestyle;
 - the physical layout and design of the accommodation;
 - details of the accommodation, including the number and type of rooms;
 - visiting arrangements;
 - personal belongings (including pets);
 - any restrictions on smoking and alcohol;
 - policies and procedures about the possession of unauthorised alcohol or drugs during your stay; and
 - arrangements with local health and social work services.

First meetings

Standard 2

You can visit or be visited by a representative of the services which you feel might be suitable and discuss your needs before making any choice.

- 1 You can meet a representative of the short break or respite care service at least once, to help you reach a decision about the service at your own pace.
- 2 If you want, family members, friends or your independent advocate (representative) may be involved in these visits.
- 3 If the break is to be in your own home you can meet the person who will provide your care, to discuss your needs.

Your legal rights

Standard 3

You can be confident that the service has written policies and practices (for example, on data protection and health and safety) covering the key areas for standards for short breaks services. These are updated in line with legislation and policy developments.

- 1 You have a written signed agreement ('individual agreement') with the service provider which defines how the service will provide for your needs.
- 2 You have a copy of this written agreement in a format you can understand.
- 3 If your short break is in a care home, you have full information on your legal position about your occupancy rights in the care home. This will include:
 - the terms and conditions of accommodation and residence;
 - payment arrangements; and
 - arrangements for changing or ending the agreement.
- 4 You can ask for, and be given, a full list of the service provider's policies and procedures which show how it complies with all relevant legislation guidance and standards relating to fire, health and safety procedures and risk management.

Positive experiences

Standard 4

You can expect to enjoy a range of positive experiences during your short break or respite.

- 1 You know that the service ensures your wellbeing and safety, whatever setting you are in.
- 2 If the break is away from your own home, the environment will accommodate you and any equipment you need in a way which supports your right to privacy and dignity.
- 3 If the service is provided in a care home you can be confident that you will be staying in a comfortable and homely environment and that the care home meets the standards for environment for care home services.
- 4 If the break is away from your own home, your views, and those of your carer or representative, about your room, will be listened to.
- 5 Where the service is provided alongside facilities for long-term care, there is separate accommodation for people using respite care. The people using the service will be of a similar age to yourself.

Management and staffing arrangements

Standard 5

You experience good quality support and care. This is provided by management and staff whose training and expertise allows them to meet your needs. The service operates in line with all applicable legal requirements and best-practice guidelines.

- 1 You know that those providing your care and support are actively encouraged to take part in training.
- 2 You know that those providing your care and support have public liability insurance and appropriate car insurance.
- 3 You can be confident that those providing your care and support are supported at all times by skilled and experienced professionals who have the time to do so.
- 4 You know that those providing your care and support are all recruited and selected through a process which includes:
 - taking up references;
 - criminal records checks, where appropriate; and
 - cross-reference to the registers of the Scottish Social Services Council, UKCC or other professional organisations, where appropriate.
- 5 You can be confident that those providing your care and support are trained and supported to meet your needs without damaging your health or theirs.
- 6 You are supported by sufficient staff who will help you in your agreed activities without unreasonable risk to yourself or others.

- 7 You can be assured that the service has policies and procedures which cover all legal requirements, including:
 - staff and training;
 - administration of medication;
 - health and safety;
 - 'whistle-blowing';
 - environmental health;
 - fire safety;
 - managing risk; and
 - proper record-keeping, including recording accidents, incidents and complaints.
- 8 You can be confident that staff know how to put these policies and procedures into practice. They have regular training to review this and to learn about new guidance.
- 9 You can be confident that those providing your care and support will not use restraint at all unless it is permitted by law and even then, restraint will not be used until other interventions have failed. If you are ever restrained, this will be recorded and you can expect to be supported after any episode of restraint.

Individual agreement

Standard 7

As far as possible, the individual agreement covers your own and your carer's wishes of the service and what is to be provided. It records an assessment of your needs that is carried out by the provider. The agreement is in a language and format that you can easily understand.

1 The individual agreement includes:

- a record of the agreed service, including what the service is, how long it will last, how often it is provided, its purpose and cost;
- a record of your hopes and your carer's hopes of the service and how the provider will meet them;
- arrangements for reviewing the service being provided;
- what you prefer to be called;
- a record of your individual choices and preferences, including social and recreational activities;
- for a break away from your own home, a record of your preferred accommodation;
- your personal care needs;
- your food preference and any special dietary needs;
- the management of medication and any other medical procedures;
- cultural, faith, religious and spiritual needs;
- risk-taking;
- contact details; and
- procedures to be used in emergencies.
- 2 You can meet a member of staff to discuss your needs before agreeing any service. With your permission, information will be made available to the provider to help them decide if they can respond to your needs.
- 3 You can invite anyone you want to support you in making your needs known.

- 4 Your carer or representative can contribute to any discussions about your needs in relation to what the service can offer.
- 5 You have your wishes listened to, and respected, over the purpose of the short break service. The needs and wishes of your carer or representative are taken into account.
- 6 You can be confident that the service provider records the views of your carer or representative separately and considers them when finalising details of the service that will be provided.
- 7 If your views and those of your carer about the delivery of the service are different, you will both be helped to reach an acceptable compromise.
- 8 You know that the individual agreement takes account of the other services that are provided as part of your care package.
- 9 A copy of your individual agreement is given to you, and also to your carer or representative if necessary, and with your permission.

7-18 Using the service (standards 7 to 18)

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Using the service

Introduction to standards 7 to 18

Short breaks and respite care should provide a positive experience for you and a break for carers from the main caring tasks. This positive aspect should be evident, even when the break takes place in an emergency.

Starting to use the service – making choices

Those providing your care and support will know why the service has been provided for you and your carer. They will be able to talk to you about any worries that either of you may have when you start to use the service and the choices and decisions to be made.

Feeling safe and secure

You have the right to feel safe and secure during your short break or respite care. You will be able to choose the risks you want to take in the same way as you usually do, as long as there is a sensible balance between your needs and preferences and those of others.

Exercising your rights – expressing your views

The service provider must always respect and actively promote your rights as a citizen. Using the service, you keep your human rights and you also have a responsibility not to infringe the rights of others. The provider must take seriously your comments, concerns and complaints about the quality of the service and your experience of it. They are your way of contributing to and influencing how the service is run.

Lifestyle – social, cultural and religious belief or faith

The standards in this section make it clear that you can continue to live your life in line with your own social, cultural or religious beliefs or faith.

Eating well and keeping well

Good, nutritious food and drink are important in keeping and improving your health. Individual choices of food and drink vary, as do dietary needs. Having your own needs and choices met is an important part of the quality of day-to-day life. Keeping healthy or regaining your health are important to your wellbeing and quality of life. You have a right to have your health needs met and to have support in using the full range of healthcare services. You also have a right to have your medication arranged efficiently and safely if you want this.

Private life and daily life

In the short break or respite care, you continue to have the right to a private life. Your individual agreement will let the service know what activities and interests you have and how to help you to stay involved in these or develop new interests.

Supporting communication

People may use different languages or methods of communication for a variety of reasons. As a result, they may have difficulty in making themselves understood. However, being able to communicate is essential in playing an active part in daily life and you should get help to do so if you need it.

Starting to use the service

Standard 7

You are welcomed by those providing your care and support and are clear about who will help and support you.

- 1 You have a named member of the service providing your short break who will co-ordinate your individual agreement, monitor its progress and stay in regular contact with you and everyone involved.
- 2 You can discuss your needs at all reasonable times with that person.
- 3 If you are not certain about whether the service is right for you, you can speak to those providing your care and support to help you with your final decision.
- 4 If you have to move into respite care because of an emergency or crisis:
 - every effort will be made to meet your preferred option before the service starts. The needs and wishes of your carer or representative will be taken into account when agreeing the service that will be provided;
 - where information relating to your care needs is not available, a full assessment of need will take place within 72 hours of you taking up the service. Your carer or representative may be able to take part in the assessment;
 - the provider and your care manager will keep in touch to make sure that the service suits your needs;
 - the provider will help you keep up to date about the crisis and how it may affect how long you stay;
 - within 24 hours, you will meet a member of the provider's staff to discuss the service in more detail and your carer or representative will be kept fully informed about your care, unless otherwise specified; and
 - the provider will recognise any needs you may have as a result of the emergency placement.

Making choices

Standard 8

You can take part in deciding what the service will provide to meet your assessed needs.

- 1 You can contribute to the way the service is delivered, according to your skills and interests.
- 2 Your carer and/or representative has the same opportunities to contribute to the way the service is delivered.
- 3 Your carer and/or representative may be involved in making decisions if you want them to and if you cannot express your preferences.
- 4 Your individual agreement reflects your individual choices and preferences. If it is not possible to provide for your preferences, the reasons will be discussed with you and the outcome recorded.
- 5 You can choose whether you want to keep control of your personal affairs during your short break. You can get help with your financial arrangements if you need it.

Feeling safe and secure

Standard 9

You feel safe, secure and comfortable in the environment where the service is provided. Your right to be able to take reasonable risks is also respected.

- 1 You choose how you spend your time, depending on your own health and wellbeing and risk assessment. The provider may ask your carer and/or representative for their views.
- 2 If the short break is in the home of another family (as in family-based respite), a risk assessment of the living arrangements will have been carried out and any recommendations will be followed.
- 3 Your carer or representative is kept fully informed of any accident or incident that happens during the short break or respite care.
- 4 You can be confident that you will be in an environment that is free from bullying, harassment, discrimination and any other form of abuse.
- 5 In a short break away from home, you know that:
 - your living environment is safe and secure;
 - you can safely store your personal belongings in your room;
 - all equipment that is used to help you in your daily life will be regularly serviced and maintained;
 - you are kept informed of all emergency procedures in a way that is suited to your needs;
 - your carer or representative is asked about any special needs you may have which need to be considered in an emergency;
 - your personal belongings will be used only by you unless you want to share their use and have given your permission. Only you use your clothing and you are not expected to wear other people's clothes; and
 - staff will make sure that your clothing and personal belongings are clearly marked.

Exercising your rights

Standard 10

You keep your rights as an individual.

- 1 You are confident that staff will treat you politely at all times and always respect your individuality.
- 2 You are called by your preferred name or title at all times by staff.
- 3 If you need help, your request will be dealt with as soon as possible.
- 4 Confidential information about you is only shared with others if you give permission.
- 5 If any information cannot be kept confidential, you will be told why and who has the right to see it.
- 6 You can be sure that your confidential records are held securely.
- 7 You have access to any information or records held about you unless there are confidentiality policies or legislation that prevent this.
- 8 You can challenge any information held about you which you feel is misleading and which may affect the service provided.
- 9 You can be supported to retain your civil rights (for instance, voting in an election).

Expressing your views

Standard 11

You are encouraged and supported to make known your views on any aspects of the service.

- 1 You can freely discuss any concerns you have with those providing your care and support or the appropriate member of staff or management.
- 2 You know how to make a complaint or comment about the service. You are also aware of the procedure for making complaints directly to the Care Commission.
- 3 You are not penalised in any way by the service if you have made a complaint. You do not have to give your name when you make a complaint if you do not want to.
- 4 Your carer or representative has an equal opportunity to make his or her views about the service known and can receive support to do so, if necessary.
- 5 The provider deals with concerns and complaints quickly and sympathetically, and provides full information about what happens as a result.
- 6 You are encouraged and supported to use an independent and confidential advocacy service that can act for you, if you want to.
- 7 If you have an independent advocate (representative), staff will listen to what he or she has to say on your behalf, as if you were expressing the views yourself. They will take seriously any suggestions or proposals resulting from you using an advocate.
- 8 You can play a part in the Care Commission's inspection of your service, if you want to.
- 9 The manager of the short breaks and respite service will give you a copy of the most recent Care Commission inspection report about the service, so that you and your representative can look through it in your own time.

Lifestyle – social, cultural and religious belief or faith

Standard 12

Your social, cultural and religious beliefs or faith are known and respected. You are able to live your life in keeping with these beliefs.

- 1 Those providing your care and support will be properly informed about the implications for you of your social, cultural and religious belief or faith.
- 2 You are given the opportunity and support you may need to practise your beliefs, including keeping in touch with your faith community.
- 3 Your holy days and festivals, birthdays and personal anniversaries are recognised and ways found to make sure you can observe these as you choose.
- 4 Your routines, preferences and any cultural needs relating to your personal care will be respected, for example, the way you look after your skin and hair.
Eating well

Standard 13

Your meals are varied and nutritious. They reflect your food preferences and any special dietary needs. They are well prepared and cooked and attractively presented.

- 1 You can be confident that those providing your care and support will make sure that your meals reflect your choices and preferences, including ethnic, cultural and faith ones, and take account of any special dietary needs (for example, if you are a vegetarian or have diabetes).
- 2 You can be confident that your meals are well prepared and well presented and that all food handling follows good food hygiene practices.
- 3 You must be able to eat and enjoy your food and drink. If you need any help at mealtimes (for example, adapted cutlery or crockery, a liquidised diet or help from your those providing your care and support or care staff), the service will arrange this for you.
- 4 Those providing your care and support will note anything that may affect your ability to eat or drink, such as your dental health. If there are concerns, they will support you to get advice and help if you want.
- 5 If you are unable to say if you are getting enough to eat or drink, those providing your care and support will keep an eye on this for you if you want them to. If there are concerns, they will explain them to you or your representative. With your agreement, they will take any action needed, such as seeking advice from a dietician or your GP.
- 6 If your short break takes place away from your home, you are free to eat your meals wherever you like, for example in your own room or in the dining room. You can eat them in your own time and you can have snacks and hot and cold drinks whenever you like.

Keeping well – healthcare

Standard 14

You can be confident that the service knows your healthcare needs and arrangements are in place to meet them in a way that suits you best.

- 1 You continue to be registered with your usual GP and dentist. If this is not possible, arrangements will be made in advance for you to be registered as a temporary resident with the GP and dentist of your choice from those providing services in the area.
- 2 You can be confident that, if you were receiving healthcare services (for example, attending hospital clinics, physiotherapy or counselling) before your short break and you still need them, arrangements are made to ensure that you continue with them.
- 3 You can expect those providing your care and support to be aware of issues about the assessment and management of any symptoms you may have and how to access any specialist services.
- 4 If you become ill or your health is not improving, you know that your doctor or other relevant healthcare team member will be contacted, if you cannot do so yourself.

Keeping well – medication

Standard 15

If you need to take medication, those providing your care and support know this and there are arrangements in place for you to take your medication safely and in the way that suits you best.

- 1 You can be confident that the service knows whether or not you are taking medication and tells those providing your care and support about this.
- 2 If your short break takes place away from home:
 - you can choose whether to manage your own medication, unless there are specific legal provisions applying to you that prevent this;
 - if you are managing your own medication, you will be given your own safe place for keeping it. If you need it, you will also have special storage somewhere else (for example, in a fridge) that is accessible to you;
 - you can get help with ordering and collecting any prescriptions you may need during your short break;
 - if you have your medication managed for you, you can be confident that the service has comprehensive systems for ordering medication and for its safe storage and administration, and for the safe disposal of unused medicines. Those providing your care and support or care staff know about these systems and follow them; and
 - if you are on medication that someone else needs to administer (for example, an injection), this will be arranged for you and will be given in a way that recognises and respects your dignity and privacy, as set out in your individual agreement.
- 3 If you have any questions about your medication which those providing your care and support cannot answer, they will help you to get the advice from your community pharmacist, GP or another member of the primary care team.

- 4 You can expect those providing your care and support to be aware of issues around the assessment and management of any symptoms you may have, including pain, and how to access any healthcare services if there are any concerns.
- 5 You can be confident that those providing your care and support will monitor your medication and the condition for which it has been prescribed. If there are any changes or concerns about the medication or the condition, they will get medical advice, if you agree.
- 6 If you are capable of understanding the need to take medication and what will happen if you do not do so, but you refuse to take it, those providing your care and support must respect your wishes.
- 7 You may not understand that you need to take medication and what will happen if you do not do so. If so, there are legal powers² that allow other people to give permission for you to receive treatment, if it is necessary for your health and welfare.

² Adults with Incapacity Act 2000; Mental Health (Scotland) Act 1984

Private life

Standard 16

You have the right to a private life.

- 1 Your personal care needs are met in a way that respects and meets your need for privacy.
- 2 If your short break takes place away from home and you need help to meet your personal care needs, you can choose who helps you, depending on which staff are available, your personal wellbeing, and health and safety requirements.
- 3 Your wishes regarding personal space are respected wherever possible, in line with the type of service provided and the physical space available.
- 4 Those providing your care and support recognise that your sexuality, sexual needs and preferences are important to you. They accept and support your right to have intimate relationships that you have consented to if it is legal to do so.
- 5 If your short break takes place away from home, you are consulted beforehand about visits or visitors.
- 6 Your belongings are treated with respect.
- 7 Those providing your care and support in your own home will only go into those parts of your home that you have given permission for, except in exceptional circumstances.

Daily life

Standard 17

You make choices and decisions about day-to-day aspects of your short break or respite care and about how you spend your time.

- 1 You receive information in a way that you can understand and that will help you to follow your interests and chosen activities.
- 2 You can keep up relationships with family, friends, carers and relatives and links with your own community. If you want to, you will be supported to do so.
- 3 You have support in making the most of opportunities to meet other people and develop new relationships or to take part in new activities if you want to. Your carer's views may be considered when agreeing what activities you can take part in. The individual agreement will record them.
- 4 You have opportunities to take part in relaxation and activities which are enjoyable and take account of your preferences, age, abilities and culture.
- 5 You have help if you want it to keep up your personal appearance, taking account of your preferences, age, comfort, fashion and culture.
- 6 You can be confident that, in a short break away from home, none of your opportunities will be affected because you are only staying for a short time.
- 7 You can be confident that, where the service provides transport, this will be available to help you maintain your existing relationships and activities.

Supporting communication

Standard 18

You have help to use services, aids and equipment for communication if your first language is not English or if you have any other communication needs.

- 1 You can be confident that communication support is available for you at all times.
- 2 You have help to keep in touch with your family, carer and friends, if you and your family, carer and friends want to.
- 3 You can communicate in whatever way you want, at any time and at your own pace.

19 Going home or moving on (standard 19) 19 Ending the short break or respite care

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Going home or moving on

Introduction to standard 19

The short break or respite care may be part of an accepted routine of breaks from living with your family or on your own. It may be a stepping stone to greater independence. Whatever the reason, the support and care you receive then should prepare you for moving on or going home again.

Ending the short break or respite care

Standard 19

You are involved in plenty of time in planning and discussing the best way to prepare for you going home or moving on. The planning and discussion involve your carer or representative (or both) and staff.

- 1 You know when and where your next short break will be. Your carer and/ or representative also knows when it will be.
- 2 You can choose what information is shared with your carer or representative. Where your ability to choose or communicate is impaired, your carer or representative will learn about the short break on a need-to-know basis only, to help them to respond when you return.
- 3 You can be confident that any requests from your carer or representative for information on anything to do with your short break are properly responded to. If there is anything in the organisational policies and procedures which prevents them from receiving this information, this will be made known to them.
- 4 You can be confident that the information that you take with you is complete and has been collected with your involvement and agreement.
- 5 You are supported to keep in touch with any friends you have made, as long as those involved all agree.
- 6 You take part in regular reviews of your respite care service to make sure it continues to meet your needs. Any review considers the needs of your carer or representative as well.
- 7 You can ask to alter the arrangements at any time during the agreed period of service, unless doing so would harm you or put your health in danger. The service provider will tell you (and your carer if necessary) of any costs involved.

Annex A

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Annex A Glossary

Advocate or Advocacy

A person independent of any aspect of the service or of any of the statutory agencies involved in purchasing or providing the service, who acts on behalf of, and in the interests of, the person using the service. An advocate can be helpful if a person feels unable to represent him or herself.

Assessment

The process of deciding what a person needs in relation to their health, personal and social care, and what services must be put in place to meet these needs. An assessment is undertaken with the person, his or her relatives or representatives, and relevant professionals.

Carer

A person who supports or looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

Complaints process

Clear procedures that help the person using the service or others to comment or complain about any aspect of the service.

Format

Information presented in a layout that is suitable for you. This could be in easy-read language, braille, on tape or on disk.

Individual agreement

An individual agreement records your hopes of the service and your needs, and how the provider will meet these.

Personal care

Help with day-to-day physical tasks and needs of the person cared for, including helping them to remember to do things such as eating and washing.

Primary care team

General Practitioner and other health professionals who provide healthcare in the community.

Representative

A person acting on behalf of a person using the service, who may be a relative or friend.

Restraint

Control to prevent a person from harming themselves or other people by the use of:

- physical means (actual or threatened laying on of hands on a person to stop them carrying out a particular action);
- mechanical means (for example, wrapping someone in a sleeping bag or strapping them in a chair);
- environmental means (for example, electronic locks or video surveillance); or
- medication (using sedative or tranquilising drugs for the symptomatic treatment of restless or agitated behaviour).

Risk management

A systematic approach to the management of risk, to reduce loss of life, financial loss, loss of staff availability, safety, or loss of reputation.

UKCC

United Kingdom Central Council for Nurses, Midwives and Health Visitors. The UKCC will be replaced by the Nursing and Midwifery Council (NMC) by April 2002.

Whistle-blowing

The disclosure by an employee (or professional) of confidential information which relates to some danger, fraud or other illegal or unethical conduct connected with the workplace, be it of the employer or of his fellow employees. (Lord Barrie QC 1995)

Annex B

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Annex B Useful reference material

Legal

The Adults with Incapacity (Scotland) Act 2000

Under this Act anything that is done on behalf of an adult with incapacity will have to:

- benefit him or her;
- take account of the person's wishes and those of his or her nearest relative, carer, guardian or attorney; and
- achieve the desired purpose without unduly limiting the person's freedom.

The Children (Scotland) Act 1995

The Act puts children first. Each child has the right to:

- be treated as an individual;
- form and express views on matters affecting him or her; and
- be protected from all forms of abuse, neglect or exploitation.

Parents and local authorities have rights and responsibilities in achieving the balance of care.

The Data Protection Act 1998

The Act covers how information about living, identifiable people is used. All organisations that hold or process personal data must comply.

The Disability Discrimination Act 1995

This wide-ranging Act, which came into force in 1996, makes it illegal to discriminate against disabled people in employment, access to goods, services, transport and education.

Fire Precautions (Workplace) Regulations 1997 (as amended)

The Regulations place a responsibility on employers for carrying out risk assessments in relation to premises. The risk assessment is a means of providing fire precautions for the safety of people using the premises.

The Health and Safety at Work etc Act 1974

The Act is the basic piece of health and safety law that covers everyone who is affected by work activity. It places the burden of legal responsibility for health and safety at work with the employer.

The Human Rights Act 1998

The Act incorporates the European Convention on Human Rights into Scots and English law in relation to the acts of public bodies. Its purpose is to protect human rights and to maintain and promote the ideals and values of a democratic society. The Articles of Convention include:

- freedom of thought, conscience and religion;
- freedom of expression;
- freedom of assembly and association;
- the right to have respect for private and family life; and
- the right to marry.

The Mental Health (Scotland) Act 1984

Currently under review, the Act provides for the compulsory detention and treatment of people with a mental disorder.

The Misuse of Drugs Act 1971

The Act is the main law for drugs control in the UK. It prohibits the possession, supply and manufacture of medicinal and other products except where these have been made legal by the Misuse of Drugs Regulations 1985. The legislation is concerned with controlled drugs and puts these into five separate schedules. Anyone who is responsible for storing or administering controlled drugs should be aware of the content of the Misuse of Drugs Regulations 1985 and the Misuse of Drugs (Safe Custody) Regulations 1973.

The Police Act 1997

Part V of the Police Act 1997 is expected to be implemented in April 2002. This provides for the Scottish Criminal Record Office to issue criminal record information certificates to individuals and organisations.

The Public Interest Disclosure Act 1998

The Act protects workers who 'blow the whistle' about wrongdoing. It mainly takes the form of amendments to the Employment Rights Act 1996, and makes provision about the kinds of disclosures which may be protected; the circumstances in which such disclosures are protected; and the persons who may be protected.

The Race Relations Act 1976

The Act makes racial discrimination illegal in employment, service delivery, training and other areas.

The Race Relations (Amendment) Act 2000

The Act makes racial discrimination illegal in public activities that were not previously covered. It puts a general duty on public organisations to promote race equality.

The Regulation of Care (Scotland) Act 2001

The Act establishes a new system of care regulation covering the registration and inspection of care services against a set of national care standards. The Act also creates two new national, independent bodies, the Scottish Commission for the Regulation of Care, to regulate care services, and the Scottish Social Services Council, to regulate the social service workforce and to promote and regulate its education and training.

The Rehabilitation of Offenders Act 1974

The Act enables some criminal convictions to become 'spent' or ignored, after a rehabilitation period. The rehabilitation period is a set length of time from the date of conviction.

The Sex Discrimination Act 1975

The Sex Discrimination Act 1975 makes it unlawful to discriminate on grounds of sex or marital status in recruitment, promotion and training. The Act also covers education, the provision of housing, goods and services and advertising.

Policy

Aiming for Excellence: Modernising Social Work Services in Scotland 1999

The White Paper sets out the proposals to strengthen the protection of children and vulnerable adults and to make sure high quality services are provided. The Scottish Commission for the Regulation of Care is an independent regulator set up for this purpose.

The Way Forward for Care

The Scottish Executive Policy Position Paper of July 2000 develops the proposals set out in Aiming for Excellence. It includes proposals for regulating independent healthcare.

Our National Health 2000

The health plan aims to improve Scotland's health and close the health gap between rich and poor, restoring the NHS as a national service and improving care and standards.

Renewing Mental Health Law 2001

The Scottish Executive's proposals for changes to existing legislation arising from its consideration of the Review of the Mental Health (Scotland) Act 1984.

The same as you? 2000

A Scottish Executive review of services for people with learning disabilities.

Other Useful Reference Material

Administration of medicines

Royal Pharmaceutical Society of Great Britain (2001) *The Administration* and Control of Medicines in Care Homes.

UKCC (2000) *Guidelines for the administration of medicines.* Central Council for Nursing, Midwifery and Health Visiting (UKCC).

UKCC (2001) *Position statement on the covert administration of medicines.* Central Council for Nursing, Midwifery and Health Visiting (UKCC).

General

Approaches to Respite Care in South Lanarkshire (2000) South Lanarkshire Council.

Carers Views on Respite (2000) Carers of East Lothian.

Caring, Respite and Quality (2000) Fife Community Care Forum.

Discussion Paper on Respite Care (1996) Fife Mental Health Survivors Group.

Fife Consultation on Respite Care (1997) Shared Care Scotland.

Gie's a break (1999) Fife Mental Health Respite Care Group.

Respite Questionnaire (1998) Princess Royal Trust Highlands Carers Project.

Respite Questionnaire – Parent Carers (1998) Princess Royal Trust Highlands Carers Project.

Restraint

Harris, J., Allen D., Cornick, M., Jefferson, A. & Mills, R. (1996) *Physical Interventions: A policy framework.* Kidderminster: British Institute of Learning Disabilities.

Mental Welfare Commission (1998) *Restraint of Residents with Mental Impairment in Care Homes and Hospitals.* Edinburgh: Mental Welfare Commission.

Further copies are available from The Stationery Office Bookshop 71 Lothian Road, Edinburgh EH3 9AZ Tel 0870 606 55 66

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