Primary and Community Care Directorate Please note that this circular has been replaced by <u>DL(2015)11, dated 28 May 2015</u>

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Dear Colleague

### NHS CONTINUING HEALTHCARE

This letter provides revised guidance on NHS continuing health care and replaces previous guidance contained in <u>MEL (1996) 22</u>.

This updated guidance is issued with immediate effect. The Scottish Government will m onitor the use of the guidance over the following 12 months.

Chief Executives must ensure that this letter and the attached guidance are br ought to the attention of all relevant staff.

Yours sincerely

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CEL 6 (2008)

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#### Addresses

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# NHS CONTINUING HEALTH CARE

#### 1 INTRODUCTION

- 1. The way in which health and social care services are delivered in Scotland has changed significantly over the last 15 years. Care has increasingly moved from an institutional base to one of personalisation. Scottish Government policy is to continue this shift in the balance of care, providing care and treatments nearer to people's homes.
- 2. In light of the policy and legislative changes it was commonly agreed that existing guidance on NHS continuing health care needed to be updated. The Cabinet Secretary for Health and Wellbeing stated, in July 2007, that she wanted a review of the current guidance with an updated version taking account of legislative and policy changes and taking account of acknowledged good practice in the delivery of health and social care. This guidance fulfils that commitment.

## 2 PURPOSE OF GUIDANCE

#### Aims and objectives of revised guidance

- 3. This guidance covers the responsibilities of the NHS in Scotland for providing continuing health care services to the population and replaces previous guidance contained in MEL (1996) 22<sup>1</sup>.
- 4. It does not alter existing NHS responsibilities for continuing health care but aims to update and clarify the current guidance to take account of the legislative and policy changes in care provision since 1996.
- 5. The guidance aims to enable professionals, patients and carers to better understand the policy intentions and their application and to create a more consistent approach to the use of the guidance across Scotland. It also aims to ensure that people receive the appropriate level and type of care related to their needs within the relevant legal, policy, clinical and resource context.
- 6. The overall objectives of the guidance are to:
  - Promote a consistent basis for the assessment of, and provision of, NHS continuing health care.
  - Ensure care provision is based on robust assessment and decision making processes.
  - Ensure that patients and their carers have access to relevant and understandable information.
  - Agree a basis for the development of effective local agreements on inter agency and multi disciplinary working in relation to NHS continuing health care.
- 7. The updated guidance is issued with immediate effect. The Scottish Government will monitor the use of this guidance over the following 12 months.

#### NHS continuing health care - what is it?

- 8. NHS continuing health care is a package of continuing health care provided and solely funded by the NHS. The NHS, and not the local authority or individual, pays the total cost of that care. NHS continuing health care may be for prolonged periods but not necessarily for life and entitlement should be subject to regular review.
- 9. Eligibility is explained at section 4. Due to the level of specialist treatment required it is expected that NHS continuing health care will be provided in a hospital ward, hospice or a contracted inpatient bed, which may be based in a care home.
- 10. If a person does not qualify for NHS continuing health care the NHS will still have responsibility to contribute to that person's health needs. This care may be provided over an extended period of time to meet the physical and mental health needs of people which have arisen as a result of disability, accident or illness.
- 11. People should be able to have their health care provided according to their needs and delivered by the right professional in the right setting at the right time for the required period. Nothing in this guidance changes that fundamental principle. The

<sup>&</sup>lt;sup>1</sup> <u>http://www.show.scot.nhs.uk/sehd/mels/1996\_22.pdf</u>

guidance principally focuses on the care provision for individuals whose care needs are such that they require NHS care to be provided in an institutional setting. It also deals with certain circumstances arising where care in such a setting is assessed as not required.

#### Who may need it?

12. Any individual of any age, with any illness or disability, may be entitled to NHS continuing health care. It is entirely dependent on whether an individual is eligible according to their assessed needs and not on the diagnosis of any particular illness.

#### Core values and principles

- 13. The reasons given for a decision on eligibility should be based on the clinical needs of an individual as assessed by a multi-disciplinary team.
- 14. The NHS's responsibility to provide or commission health care (including NHS continuing health care) is not indefinite, as needs might change. This should be made clear to the individual and their family. Regular reviews should be built into the process to ensure that the care package continues to meet the person's needs.
- 15. The process of assessment and decision making should be person-centred and needs-led. This means placing the individual, their wishes and preferred models of support at the heart of the assessment and care-planning process. The individual's wishes and expectations as to how and where the care will be delivered should be documented and taken into account, along with the risks of different types of provision, when deciding how their needs might be met. It is important that the process of considering and deciding eligibility does not delay treatment or appropriate care being put in place. The Single Shared Assessment (SSA) provides a good model.
- 16. Access to both assessment and provision should be fair and consistent. There should be no discrimination on the grounds of race, disability, gender, age, sexual orientation, religion or belief, or type of health need (for example whether the need is physical or mental). Health Boards have a general responsibility under the Equality Act 2006<sup>2</sup> for ensuring that discrimination does not occur. This duty is further enhanced by the six *Fair for All*<sup>3</sup> policy strands that recognises and responds sensitively to equality and diversity within healthcare in Scotland, and encourages health practitioners and managers to strive for best practice that goes beyond the compliance of the law.
- 17. Persons being assessed, and their carers, need to understand clearly the process of the assessment for NHS continuing health care. They should receive advice and information to enable them to participate in informed decisions about their care needs. Decisions relating to eligibility, and the reasons behind them, should be transparent from the outset for individuals, carers, family, and staff.
- 18. Health Boards and local authorities should bear in mind that a carer providing regular and substantial care has a right to an assessment of their own needs as a carer. Under the Community Care and Health (Scotland) Act 2002<sup>4</sup>, NHS Boards

<sup>&</sup>lt;sup>2</sup> http://www.opsi.gov.uk/acts/acts2006/ukpga\_20060003\_en\_1

<sup>&</sup>lt;sup>3</sup> <u>http://www.fairforall.org.uk/</u>

<sup>&</sup>lt;sup>4</sup> s.2, <u>www.opsi.gov.uk/legislation/scotlan/acts2002/asp\_20020005\_en\_1</u>

have developed Carer Information Strategies. These strategies, in place since May 2007, should improve carer identification, information and training to help carers continue in their caring role.

- 19. Establishing eligibility requires a clear, reasoned decision based on evidence of needs from a comprehensive assessment. The evidence and the decision making process should be accurately and fully recorded.
- 20. A person carrying out an assessment for NHS continuing health care should always consider whether there is further potential for rehabilitation and regaining independence, and how the outcome of any treatments or medication may affect ongoing needs.
- 21. The risks and benefits to the individual of a change of location or support should be considered carefully before any move or change is confirmed. Neither the Health Board nor local authority should unilaterally withdraw from funding an existing package without appropriate reassessment and identification of the body responsible for funding.

### 3. POLICY CONTEXT

#### Legal framework

- 22. The National Health Service (Scotland) Act 1978<sup>5</sup> requires Scottish Ministers to provide a comprehensive and integrated health service to improve the physical and mental health of the people of Scotland and to provide or secure services for the prevention, diagnosis and treatment of illness.<sup>6</sup> There is also a general duty to promote the improvement of physical and mental health.<sup>7</sup> The discharge of these functions is essentially delegated to health boards. The Act requires health boards, *to the extent that they consider necessary to meet all reasonable requirements*, to provide or secure primary medical services.<sup>8</sup> Their duties under the 1978 Act include duties to provide hospital and other accommodation and medical, nursing and other services.
- 23. The Scottish Ministers shall generally make arrangements, to such extent as they consider necessary to meet all reasonable requirements, for the purposes of the prevention of illness, the care of persons suffering from illness or the after-care of such persons.<sup>9</sup>

#### Local authority responsibility for health care as part of social care

- 24. The Social Work (Scotland) Act 1968<sup>10</sup> places a duty on local authorities to promote social welfare by making available advice, guidance and assistance.<sup>11</sup> It also places a duty on them to assess needs and to provide or arrange "community care services",<sup>12</sup> which essentially means services under Part II of the 1968 Act (or under certain provisions of the Mental Health Care and Treatment (Scotland) Act 2003<sup>13</sup>).
- 25. Local authorities also have duties to provide, themselves or through others, residential accommodation with nursing to persons who appear to them to be in need of such accommodation by reason of infirmity, age, illness or mental disorder, dependency on drugs or alcohol or being substantially handicapped by any deformity or disability.<sup>14</sup>
- 26. A local authority may also, with the approval of Scottish Ministers, and shall, if Scottish Ministers so direct, make arrangements for the purpose of the prevention of illness, the care of persons suffering from illness and the after-care of such persons. Such arrangements cannot include arrangements in respect of medical, dental or nursing care, or health visiting<sup>15</sup> (although, as stated, residential accommodation with nursing can be provided by local authorities).
- 27. Local authorities have a duty to assess the needs of any person for whom they may have a duty or power to provide community care services. Therefore, local authorities have the lead responsibility for co-ordinating the assessment of all

<sup>&</sup>lt;sup>5</sup> www.opsi.gov.uk/acts/acts1978/pdf/ukpga\_19780029\_en.pdf

<sup>&</sup>lt;sup>6</sup> s1

<sup>&</sup>lt;sup>7</sup> s1A

<sup>&</sup>lt;sup>8</sup> s2C <sup>9</sup> s36(1)

<sup>&</sup>lt;sup>10</sup> www.opsi.gov.uk/acts/acts1968/pdf/ukpga\_19680049\_en.pdf

<sup>&</sup>lt;sup>11</sup> s12

<sup>&</sup>lt;sup>12</sup> s12A

<sup>&</sup>lt;sup>13</sup> <u>http://www.opsi.gov.uk/legislation/scotland/acts2003/pdf/asp\_20030013\_en.pdf</u>

<sup>&</sup>lt;sup>14</sup> s13A <sup>15</sup> s13B

community care needs, on an inter-agency basis.

28. Improving outcomes through joint working remains an important policy goal. The Community Care and Health (Scotland) Act 2002 promotes integration in other ways by enabling the delegation of functions, the transfer of resources and the pooling of budgets between local authorities and NHS Scotland.

#### **Policy Direction**

- 29. The Scottish Government want people to remain in their own homes, living as independently as possible for as long as possible. Research has consistently shown that this is what people themselves want. Government policy therefore is to support this.
- 30. The Scottish Government is committed to improving outcomes through partnership working across organisational boundaries. It encourages health and social care agencies to work together to provide joined up, community focussed services. It has recently developed a performance framework for joint working in community care which should support the Single Outcomes Agreements being developed by local authorities.
- 31. Community care has delivered a large shift in the balance of care over the last 15 years, with very significant reductions in the number of older people and adults with learning disability and mental health problems living in hospital settings and a consequential increase in people living at home or in a community setting. Over 90% of older people receiving care live in their own homes, and the vast majority of hospital patients are discharged in a timely and appropriate manner. Much of this has been achieved through partnership working between the NHS, local authority community care and housing and the voluntary and private sectors.
- 32. In addition individuals are more empowered. Self directed support through direct payments has been introduced and is being extended to all care groups, carers have new rights to an assessment and joint working has progressed through work in multi-disciplinary teams. More generally, the Scottish Government is committed to modernising services to achieve better results.
- 33. Community care services cover a wide range of health and social care activities that collectively enable older and vulnerable citizens to optimise their quality of life and to enable them to continue to live in their own homes and communities. The NHS will continue to have responsibility for the provision of services to people with certain health care needs.

#### Shifting the balance of care

34. Shifting the balance of care to people's own homes and to the community has been a key part of community care policy for some time. *Better Health, Better Care*<sup>16</sup> promotes a similar shift in the NHS. Community care services are progressing in their own right and responding positively to change around them. The long-term goals in community care of supporting people at home for as long as possible, providing choice, supporting independence and rebalancing care to people's own homes, remain. The means of achieving them is, however, shifting to more joint services (including 'one stop shops'), more intermediate interventions, more self

<sup>&</sup>lt;sup>16</sup> <u>http://www.scotland.gov.uk/Publications/2007/12/11103453/0</u>

care and self managed care including greater support for carers, and taking the opportunities of developments in telecare, telehealth and equipment and adaptations to support people more effectively in their own homes. Individual roles are changing, too, as the emphasis shifts to skilled and dedicated professional home care staff supported to carry out a more substantial home care service.

- 35. Community care services support people with care needs and their carers through home care, day care, community nursing, respite and physiotherapy, Occupational Therapy, chiropody and other professional supports. They are multi-disciplinary in form, responsive in shape and make a vital difference. Self-directed support gives service users and carers the opportunity to purchase their own services to meet social and health care needs.
- 36. Joint working between social care, health and housing is essential to its success. That reflects the changing needs on the ground and the greater numbers of people with complex needs living in the community, often supported by unpaid carers. There is considerable opportunity to build on traditional approaches by developing more joint staff and premises and one stop shops to support the community as a whole, as care services move closer to people.
- 37. For people to enjoy sustainable health and well-being, community care needs to progress its own agenda but also in particular to work with other parts of the whole system, especially acute and primary care services and housing, as well as providers in the voluntary and private sectors. People should be able to have choice and control over the services and support they can access. They should feel supported and safe in their own homes, be able to play an active part in the community, feel they have good quality care that improves their quality of life, and be as independent as possible. So services have to be geared to these ends. Not everyone will be able to remain or want to remain in their own home. In these situations every effort should be made to provide the setting that optimises their independence and quality of life. New models of care homes will play a significant role in enabling that. They also have a role to play in short term provision of step up/down and respite care to support care at home, prevention of inappropriate admissions and supporting early discharges.
- 38. Community care aims to enable everyone in the community to enjoy sustained health and well-being, especially those in disadvantaged communities. Nationally, we want to build the best possible climate to achieve that. That means enabling better, more local and faster access to integrated health and care services that shift the balance to encouraging independence and choice, and working in partnership with others to achieve better outcomes.

#### Free Personal and Nursing Care

- 39. Personal and nursing care is available without charge for everyone in Scotland aged 65 and over who needs it, whether at home, in hospital or in a care home. Free nursing care is available for people of any age who need it.
- 40. In order to receive personal care services commissioned or delivered by a local authority, or payments which allow people to choose who will provide the services to them, an individual needs to have an assessment by his/her local social work services to see if he/she needs them. The types of personal care provided will vary according to the assessed care needs.

- 41. If someone wants to have an assessment to determine their care needs they should contact their local social work services department.
- 42. For someone in a care home then the local authority will assess whether he/she needs these services and if so it will pay a fixed rate. Full guidance on free personal and nursing care is available in <u>Circular CCD5/2003</u>.<sup>17</sup>

<sup>&</sup>lt;sup>17</sup> www.scotland.gov.uk/resource/doc/55971/0015597.pdf

## 4. ELIGIBILITY FOR NHS CONTINUING HEALTH CARE

## Eligibility

- 43. The consultant (or GP in some community hospitals) will decide, in consultation with the multi-disciplinary team, whether the patient-
  - (a) needs inpatient care arranged and funded by the NHS;
  - (b) needs a period of rehabilitation or recovery, arranged and funded by the NHS; or
  - (c) should be discharged from inpatient care (see section 8).
- 44. Continuing inpatient care should be provided where there is a need for ongoing and regular specialist clinical supervision of the patient as a result of-
  - (a) the complexity, nature or intensity of the patient's health needs, being the patient's medical, nursing and other clinical needs overall;
  - (b) the need for frequent, not easily predictable, clinical interventions;
  - (c) the need for routine use of specialist health care equipment or treatments which require the supervision of specialist NHS staff; or
  - (d) a rapidly degenerating or unstable condition requiring specialist medical or nursing supervision.

## Assessment tool

- 45. We have already suggested that the Single Shared Assessment approach (see section 5.1) provides a good model. Within that approach we will develop and pilot an additional assessment tool which should help promote consistency across Scotland. It should assist practitioners in obtaining a full picture of the needs of the person being assessed and help indicate the level of care required. It should assist in providing evidence of the decision made and be part of the formal record of the decision.
- 46. It is important to note that the tool will not be a decision <u>making</u> tool. It will merely support and help to inform and justify any decision. The decision itself will remain a matter of professional judgement.

## Specific client groups

- 47. MEL (1996) 22 made specific reference to people who were near the end of life and included a section on palliative care. This revised guidance makes no distinction between any client groups. Individuals whose prognosis is that they are likely to die in the near future are entitled to a range of services to meet their needs in the same way as anyone else. We expect all agencies to ensure that these services are provided as sensitively and as practicably as possible, in a timely manner.
- 48. By March 2008 the Scottish Government will publish a plan setting out how we will implement the recommendations of the Scottish partnership for Palliative Care's report, *Palliative and End of Life Care in Scotland; the Case for a Cohesive Approach.*<sup>18</sup> This will bring a single, comprehensive approach to the provision of palliative care across Scotland.

<sup>18</sup> 

http://www.palliativecarescotland.org.uk/publications/Palliative%20and%20End%20of%20Life%20Care%20in% 20Scotland.pdf

49. The report highlights Scottish Borders Council and NHS Borders joint approach to palliative care at home as delivering a high quality service. It urged this revised guidance to more clearly emphasise joint responsibility for planning and financing palliative care.

#### 5. DECISION MAKING

#### Who makes the decision?

- 50. The decision is fundamentally a professional clinical decision, based on the outcome of the multi-disciplinary assessment. The consultant or GP, in consultation with the multi-disciplinary team, will decide whether the individual is eligible for NHS continuing health care, taking into account the matters outlined in section 4.
- 51. The assessment should be carried out by a multi-disciplinary team, which in this specific context refers to the team of health and social care professionals involved in the care of the individual concerned and should normally be done as part of the Single Shared Assessment and care/case management process.
- 52. Single Shared Assessment (SSA) was introduced following the Joint Future Group's report *Community Care: A Joint Future*<sup>19</sup>. Guidance issued in November 2001<sup>20</sup> set out expectations for SSA and the steps partner agencies should take to implement shared arrangements for assessment in community care across social work, health and housing. SSA should eliminate duplication in assessment, ensure that information is shared across agencies with the consent of the person being assessed, and speed up the delivery of appropriate services. A lead professional will co-ordinate input to the assessment, ensure the agreed services are put in place and be a point of contact for the service user. The SSA and care/case management process enables local authorities and relevant NHS bodies to improve the results for people who use services and make better use of agencies' resources and professionals' skills. Assessments should be outcome focused and have close regard to the opportunities for rehabilitation.
- 53. The multi-disciplinary team should include the clinical opinion of the consultant or the GP who has responsibility for the patient. It should also include appropriate specialists with expertise in continuing NHS health care assessment (these may be the same people) and specialist staff and specialist nursing staff who work with the individual. These staff will be involved in assessing patients who may be ready for discharge from inpatient care in a hospital, individuals in care homes and individuals referred directly from the community. Relevant social care professionals should be involved.
- 54. All relevant NHS staff should ensure that they are fully conversant with the procedures for assessing and arranging continuing NHS health care, including the basis for eligibility, the necessary multi-disciplinary assessment and decision making process, and the relevant documentation. This will help staff to inform the individual and/or their carer/family/advocate about the decision making process.
- 55. The approach should be person-centred and needs-led. This means that the working partnership between people who use services and their carers and the professionals carrying out the assessment should decide how to meet assessed needs.
- 56. NHS Boards may wish to form a panel consisting of multi-disciplinary, clinical and management representation to ensure a fair and consistent application of this

<sup>&</sup>lt;sup>19</sup> http://www.scotland.gov.uk/Topics/Health/care/JointFuture/Publications/ccajf

<sup>&</sup>lt;sup>20</sup> Circular CCD8/2001 http://www.sehd.scot.nhs.uk/publications/DC20011129CCD8single.pdf

guidance. This panel might review and finalise any decision on eligibility before the results of that decision are passed to the patient and their carers.

#### Where the decision is made

- 57. An initial screening should take place wherever the person in need of the assessment is based. This may be in their own home, a care home, a hospice or a hospital. The initial screening will determine the likelihood of, or potential for, eligibility. In addition to clear clinical needs it will take account of challenging behaviour, levels of cognitive impairment and any issues that might be a risk to the individual or others.
- 58. The initial screening outwith a hospital setting will ordinarily be undertaken by an individual's GP, community nurse or social worker as part of the Single Shared Assessment process. Relevant professionals within each discipline should consult with others where necessary. Within a hospital environment the patient's needs should be routinely monitored by medical staff.
- 59. In cases where an individual has been in an acute episode within an NHS hospital the patient should be offered every chance to receive rehabilitation and enabling treatments to maximise the opportunity to remain in their own homes. Wherever possible an assessment of longer-term needs should not be carried out within an acute setting. The integration of therapy assessment tools across all disciplines can lead to more objective assessments, based on patients' needs. Transferring patients out of an acute setting helps to return control of their lives. This means that care provision can be made that meet individual needs and avoids stereo-typical solutions.

#### Why the decision is made

- 60. There are a number of key issues to consider when assessing, arranging or reviewing the provision of NHS continuing health care, including the following:
  - The assessment should be holistic and person centred.
  - Eligibility for NHS continuing health care is not condition specific and each individual should be assessed on his/her own needs.
  - Any individual with any illness or disability may be entitled to NHS continuing health care, depending on their assessed needs.
  - People can move in and out of eligibility for NHS continuing health care as their needs change.
  - There is no limit to how long an individual can remain in NHS continuing health care as long as they continue to be eligible.
  - Individuals with a learning disability or mental illness should have an equal right
    of access to NHS continuing health care provision dependent upon assessed
    needs as any other individual. It is important that assessments in these cases
    take into account health care needs arising from behavioural and risk factors, as
    well as other relevant needs.
  - An individual's condition or the need for particular health equipment would not, of itself, make them eligible for NHS continuing health care. Similarly a need for care from, or under the control of, a registered nurse and/or GP alone is not sufficient reason for receiving NHS continuing health care. The focus should be on the total needs of the person and the care required to meet those needs.

#### When the decision is made

- 61. Individuals should be assessed for their eligibility for NHS continuing health care when it appears that they may have on going health needs. It is important that individuals who are eligible for NHS continuing health care are identified so that they receive the appropriate care package. An individual may become eligible for NHS continuing health care (or may stop being eligible) at any point in his/her lifetime. An individual may become eligible for NHS continuing health care whilst he/she is in any setting, e.g. a hospital, hospice, care home or in his/her own home. As explained in paragraph 73 details of any decision, and the reasons for it, must be provided in writing to the individual.
- 62. Following any episode of acute care in hospital, or in any circumstances and location where it is considered possible that continuing health care may be required, early consideration should be given to the need to undertake an assessment for eligibility for NHS continuing health care.
- 63. If an individual has been assessed as not being eligible for NHS continuing health care, but he/she has moved into a care home, his/her health needs should be assessed regularly or when a change in his/her health needs is noted. His/her eligibility for NHS continuing health care should then be considered.
- 64. If, following a Single Shared Assessment, it is thought that an individual may have continuing health care needs, he/she should be assessed by an appropriate, competent professional, usually a consultant within a relevant specialty to ensure that he or she is receiving the correct care package. Their care plan should also be reviewed to ensure that his/her needs are being appropriately met.

#### Record keeping

- 65. All stages of decision making in relation to the determination of eligibility for NHS continuing health care, including the assessment eligibility decision, care planning and information on the subsequent provision and monitoring of that care should be appropriately and fully documented. Decision makers should be identified and the reasoning behind the decisions clearly explained.
- 66. It should also be recorded whether or not the individual was satisfied with the decision and what information they were given, including information on the appeals process.
- 67. Such records, including where eligibility for NHS continuing health care has not been agreed, should be retained for a minimum of six years. In cases involving mental health issues the records should be kept for the lifetime of the patient.<sup>21</sup> All relevant agencies and care providers will be responsible for maintaining the relevant records.
- 68. It is expected that any part of the decision making process would be recorded in:
  - The patient's clinical records
  - The Single Shared Assessment
  - In the formal record of the multi disciplinary team

<sup>&</sup>lt;sup>21</sup> NHS MEL(1993) 152, <u>http://www.sehd.scot.nhs.uk/mels/1993\_152.htm</u>

#### Not eligible for NHS Continuing Health Care

- 69. The large majority of people, after a stay in hospital, will be able to return to their own homes and will not have any on-going care needs. However some individuals may require on-going care, which in many circumstances will be a mix of health and social care.
- 70. Some individuals may not agree with the decision that they are to be discharged and that they are therefore not eligible for NHS continuing health care. In this case they can appeal against the decision (see section 9).
- 71. Individuals who are not in the care of the NHS and who are not eligible for NHS continuing health care will continue with their existing package of care.

#### Review of decision

72. A patient or their carer or advocate is entitled to ask for a review of the decision on eligibility for NHS continuing health care if they do not agree with the outcome. This review should be referred to an appropriate and competent clinical professional. Should the patient, carer or advocate remain unhappy with the decision they may proceed to the NHS Complaints Procedure (see also section 9).

#### 6. PATIENT INFORMATION

#### Advice for patients and carers

- 73. It is important that information on assessment, eligibility, decision making processes and appeals should be made available to patients and their carers, who should be actively involved in any decisions. To this end Health Boards should ensure that the eligibility and the assessment process are clearly explained to both the patient and their carer at an early stage. This information should be in an easy to understand format, be written from a patient's perspective and be available in any form that might be needed Braille, audio, different languages etc. and be provided in a timely manner.
- 74. As part of the Multi Disciplinary Team (MDT) assessment, health boards should ensure that all decisions, including a decision not to provide NHS continuing health care, are fully explained to the patient and (subject to patient confidentiality) their main carer. These decisions should also be fully documented as part of the Single Shared Assessment process. Copies of the assessment should be provided to patients and carers in a format appropriate to their circumstances.
- 75. Time should be taken with the patient and their carer to fully explain the rationale behind the decisions made and what this will mean for the future care of, and any financial implications for, the patient. Other avenues of funding and care should also be explained at that point.
- 76. Health Boards should produce an information leaflet on NHS Continuing Healthcare for distribution to members of the public. This leaflet should be readily available within hospitals, GP surgeries, care homes etc. (A suggested example is attached at Annex B).

#### User and carer involvement

- 77. The view of patients and any carers should be taken into account when making any decision. It should be remembered that some people being assessed have a clear idea of their needs and preferences, while others will require more time to explore their needs and consider the interventions that might help.
- 78. The outcome of the assessment should be an agreement about the individual's needs, priorities and preferences for meeting them. Individuals should receive a copy of the assessment record, unless there is a good reason to the contrary, which should be made known to them.
- 79. Assessors should take account of the views and contribution of carers when assessing the person in need. Carers should be treated and supported as partners in providing care. Where the views of the person in need are at odds with a carer's views the care manager's skills will be needed to reconcile different interests. Where appropriate, independent advocacy should be sought.
- 80. Carers should be informed of their right to an assessment to determine their ability to care and the resources needed to help them, independent of any assessment of the person they care for. The local authority should undertake or arrange such an assessment.

- 81. A carer's assessment should be provided to anyone who provides care for a disabled or elderly relative, spouse or a disabled child. CCD 2/2003<sup>22</sup> provides comprehensive advice on the rights of carers and what they can expect from a carers assessment.
- 82. In essence the carers' assessment should:
  - establish what level of care the carer is willing and able to provide, and to determine whether their caring role is sustainable;
  - determine what resources the carer needs to support them in the caring role, and decide how these resources can best be provided;
  - determine what the carer needs to maintain their own health and wellbeing, and decide how these resources can best be provided;
  - identify the care provided by a carer and the carer's views so that they can be taken into account before the local authority decides what package of care to provide to the cared-for person.
- 83. Staff should support the person to make informed choices and should agree the expected outcomes with the individual, carer and other relevant professionals or agencies. The result should be an individual care plan to meet agreed needs.
- 84. The plan should be in a format suitable to the person's circumstances and be able to be shared appropriately. It should also state the arrangements and timescale for reviewing care.

#### Advocacy

- 85. Health Boards and local authorities should provide access to mediation and advocacy services which can play an important role in exploring and resolving tensions between carers and cared-for persons and others.
- 86. Advocacy services provide support to people in situations where they are vulnerable. They help people express their views, have their own stories heard and provide a safety net.
- 87. A list of advocacy services available in each area should be made available to patients, and their carers.

#### Confidentiality

88. Patients' confidentiality should be maintained at all times within the multi-disciplinary team in line with the NHS Scotland Code of Practice on Protecting Patient Confidentiality.<sup>23</sup> All concerned should speak to either their Board's Caldicott Guardian or their Data Protection Officer for further information regarding any legal obligations they may have.

#### Competence to consent

89. As with any treatment, the individual's informed consent should be obtained before the process of determining eligibility for NHS continuing health care begins. If there is a concern that the individual may not have capacity to give their consent,

<sup>&</sup>lt;sup>22</sup> www.sehd.scot.nhs.uk/publications/cc2003 02full.pdf

 <sup>&</sup>lt;sup>23</sup> <u>http://www.confidentiality.scot.nhs.uk/publications/Final%20Code%20of%20Practice%20June03.doc</u>

consideration should be given to the issue of a certificate under part 5 of the Adults with Incapacity (Scotland) Act 2000<sup>24</sup> to allow necessary treatments to be carried out.

- 90. Any person may elect a family member or other person (who should be independent of LA or NHS body) to advocate on their behalf. Even where this is not the case, the views and knowledge of family members should be taken into account, where consent has been given to seek these views. If the treatment in question is subject to the 2000 Act then the views of the nearest relative, primary carer and named person where there is one should be taken into account where reasonable and practicable to do so.
- 91. When carrying out the multi-disciplinary assessment the multi-disciplinary team should take into account the person's ability to make clear, informed decisions. To that end an assessment of the patient's mental capacity may be required. A guide to communication and assessing capacity is available on the Scottish Government website.<sup>25</sup>
- 92. The Adults with Incapacity Act may apply in the case of adults for whom major decisions need to be made who:
  - have complex and/or significant care needs; and
  - may be incapable of making major care decisions
- 93. In such cases the multi-disciplinary team should establish, at an early stage in the assessment process, whether the person has granted a power of attorney, whether a guardian has been appointed, or whether any other relevant order is in place under the 2000 Act. This can be checked with the Office of the Public Guardian. The involvement of any attorney or guardian is crucial as his/her consent may be necessary before the local authority is able to provide services to the adult.

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<sup>&</sup>lt;sup>24</sup> www.opsi.gov.uk/legislation.scotland/acts2000/asp\_20000004\_en\_1

http://www.scotland.gov.uk/Topics/Justice/Civil/awi/resources/publications/professional/assessingcapacityguide

#### 7. ARRANGEMENTS

#### Division of responsibilities between agencies

- 94. The NHS and local authorities both have responsibilities for arranging and funding care services that meet the needs of their local population. The NHS remains responsible for assessing, arranging and funding a wide range of services to meet the health care needs, both short and long term, of the population. In addition to episodes of acute health care, some people need on-going or long term care, over an extended period of time, as the result of disability, accident or illness to address both physical and mental health needs. The NHS provides a range of services to meet those needs, including primary care, rehabilitation, respite, equipment, transport and palliative care. These services are normally provided free of charge. Guidance on what the NHS may charge for is available in NHS Circular HDL (2007) 23.<sup>26</sup>
- 95. Local authorities also provide a range of services to support their population, including people whose lives are affected by disability, accident or illness. These include accommodation, education, personal and social care, leisure and other services. Local authorities may charge for some of these services.
- 96. The large majority of people, after a stay in hospital, will be able to return to their own homes and will not have any on-going care needs; however some individuals may require on-going care. The individual may need a period of rehabilitation or recovery arranged by the NHS or social work to prevent discharge arrangements breaking down, they may need to receive a package of care in a care home arranged and funded by the social work authority, or they may need a package of social and health care support to allow them to return to their own home.
- The multi-agency assessment involving patient and family/carer/advocate should be 97. co-ordinated between key professional staff from health and social work and where appropriate, housing. The assessment process should involve consultation with the patient, the patient's GP and where appropriate community health services or social work staff who are familiar with the patient's circumstances. Where a housing need is identified housing providers should be involved in these considerations at the earliest opportunity. Where discharge to housing, including supported housing, is proposed the Health and Safety considerations of the domestic situation should be taken into account. The interests of the patient should be paramount. Where a patient has no form of accommodation to go to or where successful discharge depends on housing suitable to their needs, housing information and advice may be necessary to establish if the housing is suitable. The assessment should also take account of the views and wishes of the patient, his or her family and any carer. Where other alternative provision is appropriate the proposed provider organisation should be involved at the earliest appropriate opportunity. As set out in paragraph 118, no one should be discharged from long stay care unless arrangements are in place and properly resourced for their support, care and accommodation.
- 98. For individuals being discharged from hospital to a care home, local authorities should follow existing guidance on how to manage choice of care home in a fair and consistent way following national guidance *CCD8/2003 Choice of Accommodation Discharge from Hospital.*<sup>27</sup>

<sup>&</sup>lt;sup>26</sup> http://www.sehd.scot.nhs.uk/mels/HDL2007\_23.pdf

<sup>&</sup>lt;sup>27</sup> www.sehd.scot.nhs.uk/publications/cc2003\_08.pdf

- 99. Social work staff should provide written details of the likely cost to the patient of any option which he or she is asked to consider (including where possible and appropriate the availability of welfare benefits). The costs that should be discussed will include housing or other accommodation costs additional to care costs. Social work should inform the individual that he/she may be eligible for help with these additional costs following a means test.
- 100. NHS and social work staff should ensure that patients receive written details of any care package which is arranged for them. This should include a statement of which aspects of continuing health care will be arranged and funded by the NHS.
- 101. Individuals should be informed that they may be eligible for Free Personal and/or Nursing Care.

#### Resolution of disputes between agencies

- 102. NHS Boards should ensure that procedures are in place to deal with any disputes that may arise with local authorities, other health boards, care providers or others. Ideally disputes will be resolved between appropriate officers and staff who are close to the area of dispute and aware of the issues concerned. In the event that the dispute cannot be resolved at this local level arrangements should be in place for senior management from each agency or organisation to address the problem. The use of outside bodies to act as a mediator should be a last resort.
- 103. All agencies involved should ensure that individuals are not denied necessary care while the dispute is settled.

#### **Commissioning of services**

- 104. Focussing on outcomes for individuals may need different agencies to work together to provide the best care in the most appropriate setting. This might require these agencies to pool resources and/or jointly arrange or commission services. Joint commissioning has been defined as "the process when two or more commissioning agencies act together to co-ordinate their commissioning, taking joint responsibility for translating strategy into action".<sup>28</sup> In practical terms, this means making the best use of available resources to meet identified needs.
- 105. Effective joint commissioning is crucially important in the process of developing a whole systems approach to service delivery and improving outcomes to users and carers. Joint commissioning involves a range of activities including:
  - Needs assessment
  - Financial planning
  - Working in partnership with key stakeholders, including users and carers and service providers
  - Planning innovative services
  - Effective review and redesign of services.

<sup>&</sup>lt;sup>28</sup> www.jitscotland.org.uk/action-areas/themes/indx.html

#### **Provision of services**

- 106. The setting of the care should not be a determinant of eligibility. NHS continuing health care does not have to be provided in an NHS hospital and could be provided in a care home or a hospice. When it is provided in a care home setting it is important that the circumstances that necessitate NHS continuing health care as opposed to social care are clearly stated within the contract between the Board and the care home. In all circumstances it should be established that the suggested care setting is able to meet the complex and specialist needs of those assessed as needing NHS continuing health care. The individual concerned will remain under the direct responsibility of a medical consultant.
- 107. When someone can be treated in their own home then the NHS retains responsibility to meet the health elements of that care.

#### Choice

- 108. Health Boards should follow existing guidance on involving individuals being discharged from hospital to the care home of their choice. The individual should be kept informed and involved during decisions on the care package and care planning.
- 109. Where possible and appropriate it is important for the patient to exercise choice, including decisions on 'where' and 'when' care is received, as well as 'what' services and 'how' he/she wishes to be treated or manage his/her condition. Consideration should be given to the capacity of individuals to participate effectively in decisions on the location and delivery of his/her care.
- 110. Where a patient is eligible for NHS continuing health care but a bed is not available within the provision which has been contracted for, the Health Board should seek an extra contractual referral to another hospital, hospice, or care home as close as possible to the patient's own community. The Health Board should pay for such provision.

#### Change in circumstances

- 111. Monitoring and reviewing are essential if services are to respond to changing needs. NHS professionals and others should be able to respond to changing circumstances. Responsibilities therefore should include:
  - Ensuring that appropriate arrangements are in place for monitoring and reviewing in each individual case.
  - Acting on the findings of monitoring and reviews to ensure that an individual's changing needs continue to be met through acceptable and appropriate services.
  - Assessing the ongoing need for NHS continuing health care, as part of the review process.

### 8 HOSPITAL DISCHARGE

#### Decision to discharge

112. The decision as to when a patient is clinically ready for discharge from hospital is the responsibility of the clinician in charge. However, the decision should be made as part of a multi-disciplinary process and should focus on the needs of the individual patient.

#### Discharge process

- 113. All NHS Boards, along with their local authority partners, should have in place agreed, joint discharge protocols in line with CCD 9/2003 *Framework for the Production of Joint Hospital Discharge Protocol.*<sup>29</sup>
- 114. The patient and any carer should be provided with clear written information about how hospital discharge procedures operate and what will happen if on-going care of any sort might be required. This should include information on how to appeal the decision to discharge (see paragraph 122) and the NHS Complaints Procedure (see paragraph 128).
- 115. Most people will be discharged from hospital without the need for any ongoing support and will be discharged on the day that they are clinically ready for discharge. In more complex cases it has been agreed that there is a period of up to 6 weeks beyond the clinically ready for discharge date during which all assessments should be carried out and follow-on arrangements put in place. This 6 week period is the maximum allowed and no-one should be inappropriately delayed in hospital outwith that timescale.
- 116. It is important that assessments are carried out in an appropriate setting. Acute hospital settings are not the ideal environment in which to assess someone's long term care needs. Every effort should be made to move patients to a less intensive setting in order to aid recovery and assessment.
- 117. Patients should be given every opportunity to receive intensive rehabilitation and enabling therapies, taking account of physical, mental and social functioning, that may maximise opportunities to return to their communities to live their lives as independently as possible.

#### Disagreement with decision to discharge

- 118. Where a patient has been deemed to be clinically ready for discharge and is not eligible for NHS continuing health care, they do not have the right to indefinitely occupy an NHS bed. NHS Boards should work closely with their partner agencies to ensure a safe and timely discharge from hospital, once treatment has been completed. All appropriate provisions in the community should be in place before discharge takes place and there should be no delays in achieving this.
- 119. In cases where the patient has refused all non-hospital options that have been presented, agencies should work together to implement discharge to the patient's home or alternative accommodation, with a package of care within the options and resources available.

<sup>&</sup>lt;sup>29</sup> www.sehd.scot.nhs.uk/publications/cc2003\_09.pdf

120. The procedures to be followed where a patient disagrees with the clinical decision that he/she is ready for discharge are laid out in paragraph 122. A patient should remain in hospital until the internal appeal and/or complaints process has been completed.

#### 9 PATIENT'S APPEALS PROCESS

121. This section supersedes the advice in paragraph 7 of CCD 8/2003 Choice of accommodation – discharge from hospital.<sup>30</sup>

#### How to appeal

- 122. Where an individual does not agree with the decision on eligibility for NHS continuing health care, or decision to discharge, he or she (or carer or advocate) can appeal the decision by requesting a second opinion from another appropriate, competent medical professional<sup>31</sup>.
- 123. This second opinion should ensure that:
  - An appropriate assessment has been carried out.
  - Appropriate specialists with the required expertise were involved in the process.
  - A proper record of the decision making process has been produced.
  - An independent clinical decision is reached

#### When to appeal

124. An appeal should normally be lodged when an individual expresses disagreement with the decision on eligibility for NHS continuing health care or the process undertaken in reaching a decision.

#### Who to appeal to

125. Initially the appeal should be lodged with the professional who has made the decision. The NHS Board will then appoint another competent professional with the same level of expertise, to review the decision. Help should be provided to those who might need it in terms of deciding to appeal and preparing an appeal (see paragraph 85).

#### Process

126. The second competent professional will review the documentation and re-assess the patients' needs to decide on whether the correct procedures have been followed and whether the outcome is the correct one. In cases where there are two contrasting opinions then a final decision should be made by an appropriate clinician who is a member of the relevant NHS Board. In most cases this will be the Medical Director or Director of Nursing.

#### Timetable

127. An initial review should be completed within two weeks although it is in the best interests of the patient and service providers for an agreed decision to be reached at the earliest opportunity. If after that the individual is still not happy then they should be directed to the formal NHS Complaints Procedure.

<sup>&</sup>lt;sup>30</sup> www.sehd.scot.nhs.uk/publications/cc2003\_08.pdf

<sup>&</sup>lt;sup>31</sup> i.e. a professional of the same or higher level working in the same field or a closely related field.

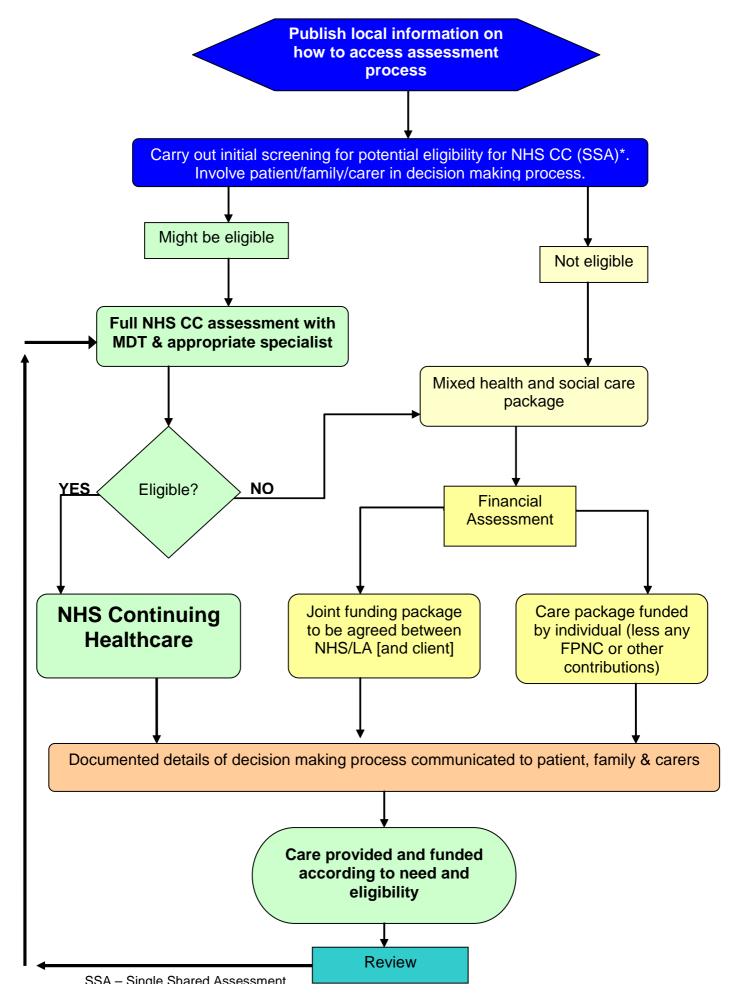
#### **NHS Complaints Procedure**

- 128. If an individual remains unhappy at the decision he or she can use the NHS Complaints Procedure to complain about that. The NHS is not a route for appeals against decisions on eligibility. However, consideration of a complaint about the process by which a decision has been reached may result in a conclusion that the process was flawed and should re-run.
- 129. In line with guidance on NHS complaints an individual must make a complaint within 6 months of the decision being given to them, or within 6 months of realising that they had a reason to complain (but no longer than 12 months after the decision).
- 130. Full details of the NHS Complaints Procedure are contained in *Can I Help You?*<sup>32</sup> This guidance supersedes sections 7.1 and 7.2 of part 4 of that guidance which excluded the review procedure for NHS continuing health care from the NHS complaints procedure

<sup>&</sup>lt;sup>32</sup> <u>http://www.show.scot.nhs.uk/publications/me/complaints/docs/1guidance010405.pdf</u>

# **Appendix 1**

# NHS Continuing Healthcare (NHS CC) Assessment Process



#### Appendix 2

TO ARRANGE AN ASSESSMENT, OR TO MAKE A COMPLAINT, CONTACT YOUR HEALTH BOARD AT:

THE SCOTTISH PUBLIC SERVICES OMBUDSMAN CAN BE CONTACTED AT:

SPSO Freepost EH641 Edinburgh EH3 0BR Tel: 0800 377 7330 Email: <u>ask@spso.org.uk</u> www.spso.org.uk/contact/index.php

#### FOR MORE INFORMATION ON NHS CONTINUING HEALTHCARE :

The Scottish Government, Partnership Improvements & Outcomes Division

www.scotland.gov.uk/Abou t/HaveYourSay/HaveYourS



# What happens if I am not eligible for NHS Continuing Healthcare?

- If you are not eligible, the NHS remains responsible to meet your ongoing health needs. You should contact your Local Authority about any other care needs.
- Remember that any decision reached by the Multi-Disciplinary Team is potentially life-changing and full consideration should be given to all of the possible outcomes. Members of the team will be available to discuss your choices.
- If you are unhappy with any decision reached by the Multi-Disciplinary Team, you can complain directly to them. If you remain dissatisfied with the decision, you have the right to have your case reviewed through the NHS Complaints Procedure, and, failing this, you can then take your case to the Scottish Public Services Ombudsman.





NHS Continuing Healthcare: Some Basic Information



# What is NHS Continuing Healthcare?

 A package of health care arranged and fully funded by the NHS for those with high health needs.

# Who can get NHS Continuing Healthcare?

- Anyone assessed as requiring a certain high level of care.
- It is not dependant on a particular disease, diagnosis, condition or age.

# How do I find out if I should receive NHS Continuing Healthcare?

- Most potential recipients will be in hospital, in which case you should speak to a member of your care team.
- Outwith the hospital setting, you should contact your GP or your social worker who will arrange a referral for assessment if they think you may qualify.

# How are decisions made?

In order to receive NHS Continuing Healthcare, you need to be assessed as eligible. The assessment itself is carried out by a Multi-Disciplinary Team (MDT), led by a clinician, using a national evaluation approach to ensure consistency across Scotland and across age groups.

# What health care needs do I need to have?

You will require ongoing and regular specialist clinical supervision as a result of:

- The complexity, nature or intensity of your health needs; OR/
- The need for frequent, unpredictable, clinical interventions; OR/
- The routine use of specialist healthcare equipment or treatments which requires the supervision of specialist NHS staff; OR/
- A rapidly degenerating or unstable condition.

# Where is NHS Continuing Healthcare provided?

• You will normally receive NHS Continuing Healthcare in a hospital ward, hospice or a contracted inpatient bed with an independent sector provider.

# What effect will this have on my benefits?

- If you are in receipt of any benefits, it is important that whenever you or a relative enters into a hospital setting, or a care home setting, that the local Benefits Agency is notified immediately of any change in circumstances.
- The actual impact of going into hospital on any benefits you may have will vary from benefit to benefit.

