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# **Living With Long Term Conditions**

## **A Policy Framework**

# Living with Long Term Conditions

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## **Foreword by the Minister for Health, Social Services and Public Safety**

The demographics of our society are changing. People are living longer and coupled with the effects of lifestyles which can adversely impact on our health and well-being, this will mean that over the next 20 years there is expected to be a significant increase in the number of people living with long term conditions. This presents a challenge to all of us to ensure that safe, effective and person-centred services are in place to support people with long term conditions.

Having a long term condition can have a significant effect on a person's life; physically, emotionally, psychologically and socially; as well as on the lives of those who care for them. This policy framework aims to ensure that as far as possible people with long term conditions are able to maintain or enhance their quality of life through high quality services and supported self management.

Working in partnership is a key concept underpinning the policy framework. People with long term conditions and their carers must be at the heart of how we plan, design and deliver treatment and care. Over recent years, Health and Social Care professionals have been working with individuals and with the voluntary, community and independent sectors to improve services and optimise health outcomes. This policy framework builds on that foundation. The framework will also help support the new model for care as set out in the Report on the Health and Social Care Review, "Transforming Your Care", published in December 2011.

In developing the framework, the Department of Health, Social Services and Public Safety has consulted with and taken the views of many individuals with long term conditions and their carers; as well as the organisations which support them and health and social care professionals. I want to acknowledge the contribution made by all those involved in developing this policy framework and in particular, the very valuable input provided by the Long Term Conditions Alliance (Northern Ireland).

I am very pleased to endorse this policy framework. It is an indicator of the commitment of all those involved in the care and support of people with long term conditions.

**Edwin Poots**

**Minister for Health, Social Services and Public Safety**

## INTRODUCTION

### Background

1. The number of people in Northern Ireland living with one or more long term condition is increasing. One of the main reasons for this is the changing demographics of the population. People are now living longer and over the next 20 years the numbers of people over 85 years of age will more than double. As people get older they are more likely to develop a long term condition or to experience co-morbidities i.e. more than one long term condition. As a result, their need for health and social care interventions increases significantly and this has implications for the delivery of health and social care.
2. Not everyone with a long term condition will be elderly: some adults will have lived with a long term condition from birth or childhood, others may have acquired a long term condition in adulthood, or been diagnosed with a condition in adulthood, for example during pregnancy. Others may have developed or exacerbated a long term condition as a result of lifestyle factors which can contribute to the increase of disease, particularly long term disease; such as diet, lack of exercise, alcohol consumption or smoking.
3. In this document a long term condition - which may also be known as a chronic condition - is defined as a disease of long duration and generally slow progression<sup>1</sup>. Long term conditions will usually require ongoing management and treatment over a period of years or decades. They are wide-ranging in their nature and may be physical, neurological or mental health conditions.
4. In February 2010, the Institute of Public Health in Ireland published a report "Making Chronic Conditions Count"<sup>2</sup>. The report contains forecasts of the population prevalence of a number of chronic (long term) conditions, namely Hypertension, Coronary Heart Disease, Stroke and Diabetes. It predicts that

between 2007 and 2020 the prevalence of these long term conditions amongst adults in Northern Ireland is expected to increase by 30%.

**Table 1 Number of Cases and Prevalence Rates for Hypertension, CHD, Stroke and Diabetes (types 1 and 2) in Northern Ireland**

	2007		2015		2020	
	No.	% of population	No.	% of population	No.	% of population
Hypertension	395,529	28.7	448,011	30.3	481,867	31.7
CHD	75,158	5.4	87,848	5.9	97,255	6.4
Stroke	32,941	2.4	38,405	2.6	42,457	2.8
Diabetes (Type 1&2)	67,262	5.3	82,970	6.0	94,219	6.6

*Source – Institute of Public Health in Ireland “Making Chronic Conditions Count”*

5. Many initiatives are already successfully underway at local level to develop services for people with long term conditions. The Department of Health, Social Services and Public Safety (the Department) is keen that this work should be built upon. The Department took the view that to support this it would be useful to develop a high level policy framework which would set out the strategic direction for the further development of services and support for adults living with long term conditions. To facilitate this, the Department organised a workshop in April 2010, bringing together a range of commissioners and providers, voluntary sector representatives and service users to identify key themes and priority areas for service development. Further information about the approach to developing this document is outlined in Annex A.
  
6. This policy framework has been developed to provide an overarching context and direction for supporting people who are living with long term conditions. It does not address directly the health prevention and promotion issues relating to long term conditions<sup>3</sup> but rather is focused on how people living with such conditions can be supported to maintain and enhance as far as possible their health and well-being and quality of life.

## **The Impact of Long Term Conditions**

7. People with long term conditions, including those with the same condition, will have very different experiences of how their condition affects them and this will often influence what they see as their needs and priorities. For many their condition will be relatively stable over a period of time with only irregular flare-ups. For others with more complex needs or with more than one long term condition, their situation may be less stable and as a result more intensive or ongoing periods of care and support will be required. For any individual the level of support required, and where that support is best provided, will depend on how their condition affects them over time.
  
8. Any long term condition has the potential to impact on individuals in various ways including their physical functioning, mood and mental well-being, employment potential, their thoughts about the future or a sense of isolation or stigma. Work undertaken by the Long Term Conditions Alliance Northern Ireland (LTCANI) has highlighted a number of key priorities for people with long term conditions. These include:
  - information - about both the condition and medication;
  - self management, particularly peer-led programmes and support;
  - support for day to day living with a long term condition, including adaptations and access to services provided by Allied Health Professionals (AHPs);
  - psycho-social support;
  - improved out-of-hours and emergency services;
  - having a point of contact when things go wrong<sup>4</sup>.

## **Managing Long Term Conditions**

9. In the past, care for people with long term conditions was generally reactive. This often resulted in substantial levels of unplanned use of hospital care services with a relatively small number of patients, many of whom had long term conditions, accounting for a high percentage of all acute bed days. As demographic changes lead to increasing numbers of people living with long term conditions, this will have a significant impact on the health and social

care system, making pressures on secondary care in particular, increasingly difficult to respond to.

10. Although it is recognised that in some instances hospital care will be essential for an individual, it is important that where possible unnecessary hospital admissions are avoided. In recent years the policy of the Department has been to provide a wider range of more responsive, accessible and integrated services in the community where it is appropriate to do so. Although community-based services are improving, more needs to be done. Figures produced by the Department for 2010/11 show that 11% of inpatients accounted for 57% of inpatient days and just 5% of inpatients accounted for 43% of inpatient days.
11. Facilitating a more community-based model of care is a significant challenge requiring a cultural shift that can also include the re-modelling of systems, the re-design of infrastructures and forward-looking resourcing. Decisions on where and how services are delivered should include an assessment of the rationale for current models of care and the impact of a transfer of care from the secondary to the community setting, including for example, the implications for staff resourcing and skills development.
12. The over-riding consideration however is that people with long term conditions are cared for in the environment that is best placed to deliver the most appropriate care and support for them.
13. Within the primary and community sector the main point of contact for people with long term conditions will usually be their General Practitioner (GP) or other member of the primary care team, such as a Practice or District Nurse or an Allied Health Professional (AHP). The development of specialist community roles and new ways of working utilising the skills of different professions through multi-disciplinary teams, including for example specialist community nurses and AHPs, have contributed to the capacity of primary and community care to play a leading role in long term conditions care and management.
14. Managing long term conditions in the primary and community sector must involve providing the information, support and early interventions that enable

people to better manage their own conditions, maintain their independence and thereby reduce potentially avoidable hospital admissions. Where people are given support to manage their own conditions they are also more likely to:

- experience better health and well-being;
- use their medicines effectively;
- remain in their own home;
- have greater confidence and a sense of control; and
- have better mental health and less depression<sup>5</sup>.

15. GPs and other colleagues in primary care can provide personal and continuous relationships to enable people to self manage their conditions while allowing for timely interventions where complications may arise. GP practice-based registers can provide a basis for the management of long term conditions and a source of information to enable resources to be directed towards those patients with greatest need.

### **Purpose of the Document**

16. The purpose of this document is to provide a policy framework for the Health and Social Care Board (HSCB), Health and Social Care (HSC) Trusts, the Public Health Agency (PHA), the voluntary and community sectors and independent care providers that will help them plan and develop more effective services to support people with long term conditions and their carers. It provides a context within which commissioners and providers can share and extend good practice and develop and improve services and practices that deliver best outcomes for patients and carers.

17. The policy framework document is not prescriptive in how people with long term conditions should be managed and supported. Rather it sets out a number of high level principles and values which should be embedded in the overall approach to management and support. The aim of the document is to secure better outcomes and help people with long term conditions, and their carers, get the best from the health and social care system. At a time of financial constraint, it will also aim to ensure that those resources that are in place are deployed as effectively and efficiently as possible to support



good practice in long term condition management and provide good value for money.

18. This document should be used as a reference point and strategic driver in the reform and modernisation of services to support people with long term conditions. Primarily it should inform and guide the development of commissioning plans, whilst also influencing how Health and Social Care Trusts and other providers deliver services at regional and local level.
19. The policy framework is also intended to be a useful source of reference for people with long term conditions, setting out the services they and their carers should expect as a result of working in partnership with HSC and other care providers. Importantly it also outlines the contribution that self management can make in ensuring the best outcomes for personal health and well-being and quality of life.
20. The document is based on the belief that improving services and support for people with long term conditions cannot be taken forward by the HSC and health professionals alone. It will involve working in partnership with people with long term conditions and their carers. It will also depend on building on the considerable amount of work already being undertaken with the voluntary and independent sectors, and with other Government Departments and agencies, to develop policies and joined-up services to support people with long term conditions and their carers.

### **Scope**

21. The policy framework outlines a general approach to developing services that will be applicable to adults with a wide range of long term conditions irrespective of care setting. It is neither disease nor condition-specific and accordingly no long term condition is singled out or identified for particular reference.
22. The document relates primarily to the support and treatment of adults with long term conditions. Children and young people with long term conditions have very specific needs and are not included within its scope; however, the

approach set out for adults may be applicable to young people making the transition to adult services.

23. The scope of this document extends to the overall health and well-being of individuals, including their mental and emotional health and well-being. In assessing the needs of individuals and their carers for information, advice, support and treatment for their condition, it is important that their overall physical, social, emotional and mental health needs are addressed as an integral part of this process.

### **Format**

24. The policy framework is broken down into a number of chapters. Each chapter considers a specific development area and contains a high level principle relevant to that area. Each chapter outlines a brief background to the development area, identifies what needs to be done to realise the principle, outlines how this can be achieved and identifies what success might look like.

25. Taken together these chapters cover a broad spectrum of development areas and principles for improving services and support for people with long term conditions. There is substantial crossover between the development areas. For example, information is important in its own right as a vehicle to help people to understand their condition but it is also a powerful tool in helping people to self manage and in empowering them to be partners in their care planning, giving them the confidence they need to make decisions about their own care.

26. None of the development areas therefore should be considered in isolation - each will impact on the others and a holistic and joined up approach to implementing them is necessary at all levels. A number of themes also run through the document. Effective needs assessment, better partnership working, improved communication, improved education and training, and empowerment of individuals and carers are all essential to the delivery of improvements across a number of the development areas.

27. Together, the principles and themes set out in this policy framework should influence and inform the further development of policies and practices which will improve the care, treatment and support for people living with long term conditions and their carers. A concluding chapter considers the way ahead for implementing the policy framework.

### **Developing the Workforce**

28. The importance of the workforce in the care and support of people with long term conditions is integral to this policy framework. References to “workforce” within this document should be taken to include those working in Health and Social Care, independent healthcare contractors such as General Practitioners and community pharmacists, as well as staff working within the voluntary, community and independent sectors.

29. Some of the areas for development, such as respecting people as partners, empowering people to take responsibility for their own health and initiating new ways of delivering care, require that the workforce is competent and confident to respond to a cultural change in how they communicate, interact with and care for people. Workforce planning and development should build on existing skills and expertise and identify essential future skills mix that will support a strategic shift in how and where care is delivered, moving away from the secondary care sector to prevention, anticipatory management and timely intervention in the community.

30. It is important also to recognise the unique contribution of carers, families and volunteers who provide valuable services that complement the care provided by paid health and social care professionals. With more care now provided in the community, carers are increasingly recognised as partners in care and it is crucial that they have the competence, confidence and support to take on these roles and responsibilities.

### **Policy Context**

31. Services and support for people with long term conditions interface with all aspects of health and social care. In developing this policy framework,

account has been taken of existing policy and strategies including the Department's regional strategy for health and well-being "*A Healthier Future*" (2005)<sup>6</sup>; the primary care strategic framework "*Caring for People Beyond Tomorrow*" (2005)<sup>7</sup>; "*Improving Stroke Services in Northern Ireland*" (2008)<sup>8</sup> "*Improving the Patient/Client Experience*" (2008)<sup>9</sup>, the Palliative and End of Life Care Strategy "*Living Matters:Dying Matters*" (March 2010)<sup>10</sup> and the *Physical and Sensory Disability Strategy and Action Plan* (published February 2012)<sup>11</sup>. In addition, this document has been influenced by the service frameworks for respiratory health and well-being; cardiovascular health and well-being and cancer prevention, treatment and care<sup>12</sup>. These service frameworks set out evidence-based standards to improve health and social care outcomes, reduce inequalities in health and social well-being and improve service access and delivery.

32. A report on a review of Health and Social Care in Northern Ireland, "Transforming Your Care", was published in December 2011<sup>13</sup>. The report proposes a future model for integrated health and social care and examines the implications of the model on ten major areas of care, including for people with long-term conditions. Implementation of this Policy Framework will support the approach recommended in "Transforming Your Care" for care provision for those with long-term conditions.
33. The policy framework has also been designed to complement strategies and service frameworks currently being developed, including the Service Framework for Older People's Health and Well-being.
34. This policy framework seeks to build on, support and reinforce the implementation of a range of strategies and service frameworks, as well as taking into account good practice models such as the National Institute of Health and Clinical Excellence (NICE) Quality Standards, to set a clear policy direction for the modernisation and development of care and support for people with long term conditions.

## PRINCIPLES

### Working in partnership

The person, and the interests of the person, should be at the centre of all relationships. People, and where appropriate their carers, must be recognised as partners in the planning of services, which should be integrated and based on collaborative working across all sectors.

### Supporting self management

Self management should provide people with long term conditions with the knowledge and skills they need to manage their own condition more confidently and to make daily decisions which can maintain or enhance their health and well-being as well as their clinical, emotional and social outcomes.

### Information to service users and carers

People with long term conditions, and their carers, should have access to appropriate and timely information and advice in order to help them manage the long term condition and maintain or enhance their quality of life.

### Managing medicines

Individualised support should be available for people with long term conditions to achieve the best possible outcome from their medicines.

### Carers

Carers should be respected as partners in the planning and delivery of services for people with long term conditions. Their health and well-being should be safeguarded through the provision of the support they need to continue in their caring role.

### Improving Care and Services

A pro-active, anticipatory approach should be taken to improve care and services for the management of long term conditions. Services should be person-centred, flexible and integrated across all sectors. Collaborative working should deliver co-ordinated treatment, care and services that are accessible at time of need, maintain or enhance overall health and well-being, support people in their own homes and reduce potentially avoidable admissions to hospital.

## CHAPTER 1: WORKING IN PARTNERSHIP

### Principle

**The person, and the interests of the person, should be at the centre of all relationships. People, and where appropriate their carers,<sup>14</sup> must be recognised as partners in the planning of services, which should be integrated and based on collaborative working across all sectors.**

### Background

- 1.1 Partnership working is about developing inclusive, mutually beneficial relationships that improve the quality and experience of care. This includes the relationships between individuals with long term conditions, their carers and service providers. It is also about relationships within and between organisations and services involved in planning and delivering health and social care in the statutory, voluntary, community and independent sectors. Effective partnership working should result in good quality care and support for people with long term conditions and their carers through identifying the respective roles and responsibilities of all parties and how these can best be brought together.
- 1.2 The person with the long term condition should be central to all partnership working. Their expertise and knowledge about how their condition affects them physically, emotionally and socially will be a key focus in the planning and delivery of care to meet their needs. Where appropriate, and with the agreement of the person with a long term condition, partnership working should also involve carers.
- 1.3 Good partnership working between individuals and health and social care providers can encourage compliance with care and treatment as well as promote a positive outlook on a service which people participate in rather than simply receive. Developing effective partnerships means ensuring that people have the knowledge, skills and confidence to play an active role in planning their own care and self managing their condition to a degree and

level that they feel comfortable with, whilst having the assurance that beyond that level support is available.

- 1.4 Good partnership working is also critical for building strong, effective relationships within and across organisations. Within an organisation this means taking a joined-up approach to designing and delivering integrated services for the benefit of service users. Excellent communication and multi-disciplinary team working are key elements to successful partnership working within an organisation and fundamental to ensuring a streamlined approach to care. The development of high quality, co-ordinated services across different care settings and sectors requires organisations and agencies to work collaboratively with each other. This will include working across organisational boundaries between statutory, voluntary, community and independent sectors.

### **What needs to be done?**

- 1.5 Working in partnership with patients and carers has increasingly become an integral part of health and social care and in particular the management of long term conditions. Moving to a position where this is the norm requires acknowledging the individual as an expert in the day to day management of their condition, including identifying their symptoms and setting personal goals. It also means encouraging people with long term conditions (and, where agreed, their carers) to actively participate in all aspects of needs assessment, condition reviews, care planning, decision-making and evaluation of care.
- 1.6 Good partnership working should be based on:
- open and honest communication;
  - respect for the experience and knowledge of the person (and, where appropriate, their carers) about their condition, circumstances and preferences for care;
  - choice, fairness, openness, trust and empathy; and
  - effective and accessible peer support.

- 1.7 Where they wish to and are able to do so, people with long term conditions should be active partners in self managing their condition. A key aspect of this will be working with health and social care providers to develop personalised care plans to help people manage their condition effectively and to have maximum independence with a level of support that is appropriate to their individual needs and capability. Personalised care plans can help the co-ordination of care by aiding communication so that all those involved in a person's care are aware of their role and how it fits into the wider care context. Care plans can help ensure that people do not feel "lost in the system" by providing information about what their care arrangements are and who is involved.
- 1.8 To help individuals take a more pro-active role in managing their long term condition they, and where appropriate their carers, should have access to the information and support they need to develop the knowledge and confidence to communicate effectively with healthcare professionals and participate in decision-making and planning for their own care. In turn, healthcare professionals may also need to develop new skills in communicating and interacting with people and their carers as partners and ensure that constructive feedback and evaluation processes are in place that will facilitate open and honest communication.
- 1.9 Improving partnership working within and between organisations requires identifying and removing barriers to effective working across all care interfaces and across disciplines and specialisms. This may involve reviewing and improving systems and processes, for example; extending the deployment of multi-disciplinary teams; identifying and addressing areas of overlap and duplication which can impede effective services; examining how arrangements for out-of-hours support can be improved; ensuring effective discharge procedures are in place to support people leaving hospital; and looking at how communication systems can be speeded up and made more effective so that people are seen by the right person, in the right place at right time. The Department's Personal and Public Involvement (PPI) policy contributes to this by inviting the involvement of individuals and organisations to inform and influence the development and improvement of services<sup>15</sup>.



1.10 Commissioners and statutory, independent and voluntary and community sector providers should build on the relationships that are already in place to identify how the services they plan and deliver can be further developed, re-designed and integrated to meet individuals' needs. In particular, this will mean harnessing the knowledge, expertise and resources of service users and carers, as well as the voluntary and community sector. Services and facilities offered by the voluntary and community sector, such as access to transport, complementary therapies, patient education programmes and peer support groups can play an important role in supplementing the services provided within the HSC.

1.11 Partnership working also means looking beyond health and social care, towards more collaborative working with other Government Departments, agencies and services in areas such as benefits, housing and employment to address the wider determinants that affect a person's health, well-being and quality of life and promoting effective approaches to address these.

#### **How can this be achieved?**

- People with long term conditions, and their carers, should have the knowledge and skills to allow them to communicate effectively with health and social care staff.
- HSC staff should have the knowledge and skills to communicate effectively with people with long term conditions and recognise and take account of the expertise of the patient in how their condition affects them.
- People with long term conditions should have a personalised care plan which recognises the expertise, experience and knowledge of all parties, but particularly the individual themselves. The detail and content of care plans will vary but should be based on full and frank discussion with the individual, or where this is not possible their carers, taking account of their needs, personal circumstances and preferences within available resources. Care plans should identify responsibility for each element of care.
- A multi-disciplinary and integrated approach to care planning and provision should be standard in working with individuals with long term conditions and their carers.

- Organisations - statutory, voluntary, community and independent - should work together in an integrated way, recognising their differing roles, strengths and expertise to ensure that care which meets individuals' needs is delivered effectively.
- Health and social care organisations should work closely with other Government Departments, agencies and organisations, in areas such as benefits, housing and employment to enhance the delivery of integrated services.

### **What does success look like?**

People with long term conditions, and their carers, are recognised and involved as partners in the planning and delivery of care. People with a long term condition have a personalised care plan, the content and detail of which reflects as far as possible their own experiences, needs and preferences. Positive, mutually beneficial partnership working is in place within organisations and also between organisations in the statutory, voluntary, community and independent sectors, to ensure integrated and co-ordinated care and support is available for people with long term conditions promptly, effectively and as and when required.

## CHAPTER 2: SUPPORTING SELF MANAGEMENT

### Principle

**Self management should provide people with long term conditions with the knowledge and skills they need to manage their own condition more confidently and to make daily decisions which can maintain or enhance their health and well-being as well as their clinical, emotional and social outcomes.**

### Background

2.1. Self management is about empowering people to take control and manage, with appropriate support, their own health. It is a person-centred approach that seeks to provide people with the knowledge and skills they need to understand their condition and its effects, to make the decisions only they can make and to become more involved in planning and decision-making about their treatment and care. Helping people to recognise the symptoms and signs of their conditions, how these can be managed effectively and how their condition may progress over time, can help them develop the confidence to take more responsibility for and control over their own condition and care. The “*Transforming Your Care*” report highlights the importance of partnership working with people with long term conditions to enable greater self care. Self management can include rehabilitation and patient education programmes as well as ongoing support from others in similar situations.

2.2 Where people have a better understanding of their condition and how to manage it, this can help to maintain or enhance their overall health and well-being and quality of life<sup>16</sup>. Self management can also provide value for money by reducing critical episodes, potentially avoidable hospital admissions and GP attendances<sup>17</sup>. As demographics change and the prevalence of long term conditions increases, self management will be crucial to ensuring that health and social care is better able to meet these challenges.

- 2.3 Self management does not mean replacing services and leaving people to manage their conditions alone and unsupported. People will vary in their ability to self manage and not everyone may be able to or wish to self manage their condition all the time. People should always have access to the level of support necessary to meet their needs, including for example, appropriate and timely reviews as well as options for self referral. The nature and amount of support required may vary over time depending on an individual's circumstances and the progression of their condition. People who are self managing their condition should know where to seek additional support and be assured that when needed, this will be available.
- 2.4 Self management is underpinned by effective partnership working between individuals, carers and care providers. Support to help people to self manage is available from a wide range of sources within the health and social care system as well as from independent, voluntary and community organisations and groups. A diverse range of rehabilitation and patient education and training programmes is available which can help provide people with the practical skills and tools they need to support self management. These programmes will often utilise the skills and expertise of health and social care professionals such as specialist nurses and allied health professionals. Many others are provided by the independent, voluntary and community sectors and are often led by people who themselves have long term conditions. Such programmes provide peer support, information, advice and practical mechanisms to help people manage their condition based on real life experiences of others.
- 2.5 The nature of self management programmes varies; some are generic and can provide education and advice to people with a range of different conditions whilst others will be condition-specific. Importantly, most programmes will signpost people to additional advice and other appropriate services both within and outside the health and social care system.

### **What needs to be done?**

- 2.6 In recent years a number of self management initiatives have been introduced, some of which have been commissioned by Trusts in

partnership with independent, voluntary and community organisations. However, no systematic approach has been taken to the introduction of these arrangements. The Department wishes to see self management support, education and training fully embedded within, and integral to, the overall approach to supporting people with long term conditions.

- 2.7 To help people to self manage effectively, a range of formal and structured programmes and informal support systems should be put in place and made fully accessible. The Health and Social Care Board and the Public Health Agency should work in partnership with HSC providers as well as the independent and voluntary and community sectors to ensure that expertise and capacity are fully utilised in the development and delivery of information, education and support programmes. Such programmes can be maximised by involving people with long term conditions and drawing on their practical knowledge and expertise.
- 2.8 People who are living with long term conditions often find the information and support offered by others in the same position affirmative and confidence-building. Many independent, voluntary and community organisations provide very effective user-led self management programmes, initiatives and support groups and these should be utilised more extensively. Healthcare professionals should be equipped to signpost individuals to non-health service sources of self management training and support.
- 2.9 Self management training and education programmes should be quality assured for up to date, evidence-based content and the teaching skills of the trainer, regardless of the sector providing the education. All healthcare professionals within the HSC and others who deliver self management programmes should have both the necessary training and the dedicated time to allow them to do so. Programmes should also be evaluated to ensure that they provide value for money and are effective in meeting the needs of people with long term conditions, including providing the information, advice and support individuals need to help them manage their own conditions over time for as long as possible.

*"I enjoyed the 6 week course, it helped me understand my illness better. I learned to live with it, I do my best and have kept my job."*

*(Female, aged 56-64 after attending an Arthritis Care course)*

*"The course was pitched at just the right level and I would be an advocate of the course for anyone with a long term health condition."*

*"This is definitely something useful for the future and I will use the skills I learned here to improve my life. I really enjoyed it and feel the benefits of it".*

*(Responses from participants on an Action Mental Health/Western HSC Trust Long Term Conditions Self Management programme)*

- 2.10 Where it is safe and appropriate to do so there is significant scope for new and emerging technologies to help people to self manage. Aids and equipment that can be used by people in their own homes to monitor their "vital signs", or to have their condition monitored remotely by healthcare staff, can make a positive contribution to helping people manage their condition more effectively. They can also provide carers with the reassurance they need to support them in their caring role. The use of such technology for self management should always be backed up by targeted and timely support and interventions from health and social care professionals.
- 2.11 The development of care pathways can also facilitate self management by describing the expected progress of a condition and setting out the steps in the care of people with the condition. Care pathways can help health and social care staff and individuals by identifying how care is planned using experience of best practice and wrapping this around the person and their needs. Care pathways should recognise the multi-faceted and inter-disciplinary aspects of managing long term conditions, identifying responsibility for care and incorporating clear plans with achievable goals of care. Self management support, where appropriate, should be a core element of care throughout.
- 2.12 People will need different methods and strategies for managing their condition. Health and social care services should recognise and as far as it

is safe and appropriate to do so, respond to the individual's preferences. People with a long term condition should have a holistic needs assessment which considers what information, treatment, support and follow-up review are required to allow them to self manage their condition. This assessment should in turn inform a personalised care plan tailored to the assessed needs and ability of the individual.

- 2.13 Personalised care plans should be developed in partnership with the individual, and where appropriate their carer, to create ownership and actively involve people in the management of their condition. They should take a holistic approach to health and social care, addressing general lifestyle and physical, social and mental health and well-being.
- 2.14 The nature of care plans will vary depending on the assessed needs of the individual but may include, for example, relevant personal information, personal goals and expectations about care, as well as other information including medication details and a record of the individual's condition. The content and level of detail in a personalised care plan should reflect and be appropriate to the nature of a person's condition, its stability, whether or not they have more than one long term condition and their individual circumstances. Where appropriate, care plans can also include details about psychological therapies and support as well as information on social care provision. A personalised care plan should always provide details on how the individual or their carer can access support and assistance when needed, in particular, where there is a sudden exacerbation or when out-of-hours help is required.

#### **How can this be achieved?**

- The HSC Board in liaison with PHA, Trusts and, as appropriate, independent, voluntary and community organisations should establish the current baseline of self management support in place in each Trust area.
- Commissioners should work to secure the provision of a range of quality assured, and regularly evaluated, rehabilitation, education and training programmes to enable self management.
- The HSC Board, PHA and Health and Social Care Trusts should work

closely with independent, voluntary and community organisations in the development and delivery of education and training programmes.

- Appropriate training should be provided to ensure those delivering self management support have the skills needed to do so.
- Innovative use should be made of new technology and equipment to help people to self manage as well as to prompt effective and timely professional intervention.
- People with long term conditions should have personalised care plans which include the outcome of needs assessments and the self management arrangements appropriate for them. Care plans should also identify shared responsibility for care, the health and social care professionals responsible for their care, and how and when to get help, particularly out-of-hours. A personalised medicines management plan should be included as part of the personal care plan.

### **What does success look like?**

Individuals across Northern Ireland have access to self management education and training to acquire the skills they need to be in control, to be informed about and to manage their condition, to deal with flare-ups, to adjust medicines, to maintain or enhance lifestyles and know how to access services, including self referral, when they are required. People feel competent and confident to manage their own long term condition with a level of support from the HSC, voluntary, community and independent sectors that is appropriate to their need.



## **CHAPTER 3: INFORMATION TO SERVICE USERS AND CARERS**

### **Principle**

**People with long term conditions, and their carers, should have access to appropriate and timely information and advice in order to help them manage the long term condition and maintain or enhance their quality of life.**

### **Background**

- 3.1 Providing people with information and advice is essential for giving them a better understanding of their condition, symptoms and prognosis, as well as how best to manage them. Information is a valuable tool in enabling individuals and their carers to be fully involved in care planning and have more control and choice over their care. It can also have positive outcomes on a person's general health and well-being and quality of life, including their mental health and well-being, by reducing anxiety, promoting self-confidence and helping people feel more in control of their lives.
- 3.2 People with long term conditions and their carers need appropriate and relevant information at different times. This includes information that relates specifically to them, for example, about their medication; as well as more general information about their condition, service provision and support networks. They may also need information about financial considerations, e.g. benefits entitlements or return to work arrangements where appropriate. Investment in providing condition specific education and information can help delay or even prevent serious complications in the long term, reduce demand on the health system and help keep people at work and independent.
- 3.3 People with long term conditions, and their carers, understand and learn in different ways. Information needs to be accessible, timely, available in a range of formats and tailored to fit individual needs and understanding. It should also be meaningful, up to date, culturally sensitive and relevant so that it can be used appropriately by the individual and their carers.

- 3.4 The timeliness of receiving information is vitally important and in certain circumstances people will be in particular need of information and support; for example, when they are first diagnosed with a condition, when their condition flares up or deteriorates, or at a period of transition or change such as moving between care settings or when a woman with a long term condition is pregnant or planning for pregnancy.
- 3.5 For many long term conditions, the information that individuals need to understand their condition or to support self management is available from many sources and in a variety of media. For other more rare conditions however this may not be the case and healthcare professionals should take account of this, particularly at the point of diagnosis when the need for information and understanding is paramount.
- 3.6 Increasingly the internet provides access to a range of websites where people can find general information and advice about their condition. It also provides opportunities for interactive learning, on-line support and information sharing, all of which can help overcome feelings of powerlessness, isolation or stigma which can sometimes be a feature of living with a long term condition. It should be recognised however that not everyone will have access to the internet and this should be considered when directing people to, or providing them with, information and advice.
- 3.7 Many HSC and National Health Service (NHS) websites, as well as those provided by voluntary and community organisations, provide a wide range of information to help people understand their condition and to support self management. Where people are directed by healthcare staff or other service providers to web-based information, it is important that the information they are signposted to is appropriate.

### **What needs to be done?**

- 3.8 Giving clear and timely information, education and training as soon as possible after diagnosis of a long term condition can enhance knowledge and understanding, empower individuals, reduce inappropriate referrals and

improve patient experience and outcomes. People with long term conditions should have the opportunity to discuss their information needs with healthcare professionals or other appropriate individuals as a pre-requisite to developing a personalised care plan. In addition to information about health and social care, people should also be signposted to appropriate services, including financial and other assistance that can help meet the assessed needs of the individual and their carer.

*“When you don’t know anything – how can you know what to ask?”*

*Comment from Carer. From “Stroke Survivors – Our Stories, in our Words” Eastern Health and Social Services Board Stroke Strategy Implementation Project*

- 3.9 Information should be made available in a variety of media and formats to suit individual needs and preferences, including for example using information provided by peers or social media and networks where this is appropriate for the individual. How information is made available should also take account of the language, the level of understanding, capacity and the cultural and social background of individuals. Where necessary, assistance should be made available to help people access, understand and make sense of information and ensure it is interpreted correctly.
- 3.10 All health and social care staff, and others whose roles require them to engage with people with long term conditions, should have the necessary knowledge and competence to communicate clearly and with sensitivity so that patients and carers understand what is happening, when it is happening and importantly, why it is happening, and that this information is provided at the right time for them. Education and training for health and social care professionals and others involved in providing care services should be in place to facilitate this.

*‘It’s strange thinking back now but I hadn’t a clue what all the words they used meant. I just nodded’*

*Quote from survey respondent, “Scoping the information and supportive care needs of people affected by cancer within Northern Ireland”, Dr David Manning, on behalf of Northern Ireland Cancer Network, 2010*

- 3.11 Given the breadth of information that is available, it is important that the HSC assesses the quality and suitability of resources being provided or referred to, using the expertise of the voluntary sector and other relevant bodies in doing so. The knowledge and expertise of the voluntary and community sector and of people who themselves have long term conditions should also be used to develop information resources.
- 3.12 The information provided to people should be reviewed and evaluated regularly to ensure it is appropriate to meeting their needs at the time and that it is effective in helping them to understand their condition and, where appropriate, participate in managing it.
- 3.13 It is also important that the needs of carers, particularly young carers, for information, training, support and advice should be identified to ensure they are equipped to take on and continue in their caring role. Information and education for carers should be provided in a timely way and avoid overload. Consideration should also be given to family members who are not necessarily carers, in particular what information they may need to help them understand their relative's condition and support and assist the primary carer. Information and support for carers should be available through death and into bereavement as required<sup>18</sup>.
- 3.14 All HSC websites should be user-friendly, appropriately linked and regularly updated. To ensure consistency, consideration should be given to the creation of a central directory of information materials which can be updated and developed as further information becomes available. This could be done, for example, through the development of a central HSC information portal.
- 3.15 It is vital however to ensure that people are not excluded from accessing information by the "digital divide". People over 65, those on low incomes and those with no formal qualifications may not use or have access to the internet and this needs to be taken into account and catered for when providing information. Particular attention is also required for people who need information but have communication difficulties because of, for

example stroke, diminished mental capacity or where English is not their first language.

3.16 Referral pathways used by care professionals should include agreed standards of information provision and signposting to other relevant services in the wider statutory, independent, voluntary and community sectors. The NHS in England has introduced the concept of 'information prescriptions' for people with long term conditions or social care need. The 'prescriptions' contain links and signposts to guide people to sources of information about their health and care – for example, information about treatments, care services and benefits advice. They also tell people where to get support and engage with others with a similar condition and provide website and contact details that people may find helpful. An initiative such as this would ensure that the HSC in Northern Ireland takes a consistent approach to providing information and should be considered.

#### **How can this be achieved?**

- The information needs of people with long term conditions, including their preferences for how information is shared, should be discussed with them as a pre-requisite to developing a personalised care plan. Information provided should be regularly evaluated for its effectiveness in meeting individual need.
- Commissioners should include patient information provision in their Service Level Agreements with providers (including the independent and voluntary and community sectors) and through the General Medical Services (GMS) Contract.
- The HSC Board, the PHA and HSC Trusts should work closely with the independent, voluntary and community sectors in the development and provision of appropriate information for people with long term conditions and their carers.
- HSC organisations should carry out assessments and quality assurance of information provided to patients and carers.
- Education and development programmes should be available for all staff engaged in information provision to ensure they have the skills to communicate effectively.

- The options for the development of a central HSC information resource, such as a HSC portal, should be explored.
- The development of 'information prescriptions' should be considered as part of the support offered to people with a long term condition.

### **What does success look like?**

People with long term conditions, and their carers, have access to the information they need, in the format and at the time when they need it, to allow them to manage their condition effectively and to understand how their condition may progress, and how their care is, and will be, planned and delivered. They know how to source the advice and support they may need on other issues affecting their well-being beyond healthcare. Health and social care staff, and others in contact with people with long term conditions and their carers, are well informed and have the ability to communicate information effectively and sensitively.

## Chapter 4: Managing Medicines

### Principle

**Individualised support should be available for people with long term conditions to achieve the best possible outcome from their medicines.**

### Background

- 4.1 Medicines play a key role in the management of long term conditions. Taking medicines safely and effectively however can be a challenge for some people, particularly the elderly, those with mental health conditions, learning disabilities or those with complex conditions requiring multiple medications. Research suggests that up to 50% of medicines are not taken as prescribed and adverse reactions to medicines are a factor in 5-17% of hospital admissions.<sup>19</sup>
- 4.2 There are many reasons for this: people may not want to take their medicines, they may have practical problems preventing them from doing so, they may feel better and discontinue the course before completion, or they may not understand the sequencing of their medication. This “non-compliance” is more of a problem when medicines are prescribed on a long term basis. By providing support and information a great deal can be done to help people to use medicines safely and effectively.
- 4.3 Medicines management services include the prescribing, dispensing and review of medicines. Effective medicines management should deliver the right treatment, at the right time, in the right place, by the right person and assist people to obtain the best outcomes from their medication. Good medicines management should mean that the individual (and where appropriate and with the individual’s agreement their carer) has better access to and advice about their medicines and should result in an improved shared and common understanding between healthcare professionals and patients.

- 4.4 People with long term conditions are likely to have a number of health professionals involved in their care including nurses, pharmacists and allied health professionals such as physiotherapists and dieticians. Changes to legislation allow suitably qualified nurses, pharmacists and some allied health professionals to prescribe medicines. The extension of non-medical prescribing to a range of healthcare professionals has and will continue to support services and outcomes, increasing accessibility and choice, reducing delays in receiving appropriate medicines and supporting improved medicines management advice in settings across the HSC.
- 4.5 Effective management of patients' medicines can support people in managing their long term condition and help shift the balance of care from hospital to home. This will require good multi-disciplinary and collaborative working across all care sectors and between healthcare professionals to minimise duplication of effort or gaps in service.
- 4.6 Effectively managing people's medication has the potential to increase compliance with prescribed medicines, reduce drug-related illness and mortality, minimise adverse drug reactions; reduce drug-related hospital admissions and maximise patient safety. Effective management is also important in ensuring the best use of medicines within available resources, to reduce drug wastage and to support the management of long term conditions within the primary and community sector.

### **What needs to be done?**

- 4.7 People with long term conditions should have their need for medicines regularly assessed and addressed. To encourage medicines compliance people with long term conditions and their carers should understand the nature and purpose of their medication and be confident about its use. This should include being aware of possible side effects and where appropriate how to counter these, and knowing how to access specialist medicines in an emergency or out-of-hours. Details about an individual's medicines regime should also be easily accessible to healthcare professionals if required in an emergency or out-of-hours situation or if the individual is admitted to hospital.



4.8 Throughout a patient's journey of care they and their carers should be supplied with appropriate information about medicines, communicated in a timely and effective way and complemented with a personal medicines management plan as part of their personalised care plan. They should also be respected as partners in planning their own care and offered encouragement and support to participate in decisions about their personal medicines management plan. People should have their medicines management plan reviewed regularly to identify medicines-related issues, including identifying any problems that might be affecting their medicines compliance or if changed circumstances may require a change in medication, for example when a woman becomes or is planning to become pregnant, when the individual's conditions deteriorates or if they develop another long term condition.

4.9 Community pharmacy offers a high level of access to the public, and pharmacists are an integral part of the primary and community care family of services. They work in partnership with GPs and other professionals in the primary and community care team to play an important role in helping people manage their condition and medicines effectively. In this way community pharmacists can help minimise adverse drug reaction; address and prevent potential exacerbations; maximise patient safety; provide structured follow up intervention; reduce wastage and improve patient outcomes. Medicines management services involving community pharmacies should be reviewed to ensure that they successfully meet the needs of people with long term conditions.

4.10 Appropriate use of remote telemonitoring should also be considered to help improve medicines compliance and as a useful tool in signalling a need for appropriate changes to be made to an individual's medication.

#### **How can this be achieved?**

- People with long term conditions should have their medicines management needs assessed, addressed and regularly reviewed as part of an individualised plan for their medicines régime within their

personal care plans.

- People with long term conditions should be respected as partners in all aspects of their own medicines management and care planning.
- Patients' access to medicines and advice should be improved by involving non-medical prescribers in the delivery of medicines management.
- Care pathways and individual care plans should be in place which signpost people to medicines management information and services.
- There should be better integration of community pharmacy services within the wider primary care sector and with other partners - community, secondary and social care - to support people with long term conditions in the community.
- Remote telemonitoring should be considered to help improve medication compliance.

### **What does success look like?**

People with long term conditions have, as part of their care plan, a personal plan for their medicines régime and are supported to care for themselves through the safe, effective and efficient use of medicines. As part of this plan, people with long term conditions, and their carers, know how to access specialist medicines out-of-hours. A medicines management service is in place for people living with long term conditions which delivers a person-centred model of care through working collaboratively across all care sectors.

## CHAPTER 5: CARERS

### Principle

**Carers should be respected as partners in the planning and delivery of services for people with long term conditions. Their health and well-being should be safeguarded through the provision of the support they need to continue in their caring role.**

### Background

- 5.1. As more health and social care services are provided in the community, informal carers play an increasingly important part in health and social care. It is important to recognise the unique contribution of carers in providing valuable services that complement those delivered by paid care services.
- 5.2 The role of carers is crucial in supporting the care and quality of life for people with long term conditions. Although not everyone with a long term condition will have a carer (and for some this will be through choice) the roles played by carers help health and social care services to function and in some cases, carers can provide a key link between the person with a long term condition and their professional care providers. It is crucial therefore, that carers have the confidence and competence to take on their caring roles and responsibilities and have the information, advice, practical support and education and training to do so.
- 5.3 Supporting carers in their caring role and in their relationship with the person cared for is crucial. Long term caring can have an adverse impact on the mental, emotional and physical health of carers and can lead to feelings of loneliness and isolation. This can be particularly so where carers are older, have a long term condition themselves, or are young carers. It can also be the case where the health of the person cared for is deteriorating or where a carer is caring for someone with a rare disease and support mechanisms may therefore be more limited.
- 5.4 It is important to recognise that carers have their own needs and aspirations and that whilst these may be closely interlinked with those of the individual

being cared for, they must nevertheless be seen as separate and distinct. A significant number of carers are of working age<sup>20</sup> and it is important that they are not forced out of employment by their caring responsibilities. Suitable support should be put in place to help carers remain in employment for as long as possible if that is what they want or need to do.

### **What needs to be done?**

- 5.5 Carers should be valued and respected, have their expertise recognised and, with the consent of the person cared for, be treated as partners in the planning and delivery of services by health and social care professionals. Importantly, carers should be given the opportunity to express their choices in caring, including the limits of their caring role.
- 5.6 Carers should have access to information about the nature and effects of the long term condition of the person they care for. Having this information will give carers more confidence to deal with any deterioration or exacerbation. Carers should also have access to information about available services for the cared-for person as well as better signposting to services and organisations that they themselves can use for advice and support. Such information should be user friendly and available in a way that meets the needs and preferences of the carer and takes into account their own capacity to care. For example, using social media and networks may help young carers in particular address any sense of isolation they may be experiencing.
- 5.7 Carers should also have appropriate training and education on the technical aspects of care e.g. use of telemonitoring equipment, aids, lifting skills, equipment and medicines. The information, services, training and support provided for carers should be flexible and responsive to the changing needs of both the person with a long term condition and their carer(s).
- 5.8 Carers have a life of their own outside their caring role with their own needs, goals and relationships. The *Carers and Direct Payments Act (Northern Ireland) 2002* imposes a legal requirement upon Health and Social Care services to advise carers of their statutory right to a separate assessment of

their needs. Carers' assessments can help identify interventions and support that may help sustain carers in their caring role. It is important that carers' assessments are undertaken in a timely manner and are not pre-empted by an emergency or carer fatigue.

- 5.9 Based on the assessment of needs, carers should have a care plan in their own right with responsive support services in place to ensure that they can sustain their caring role for as long as possible without adverse effect on their own health and well-being or their educational, social or personal development. Regular review and having a single point of contact are critical to support carers and help them to sustain their caring role.

*"I had my carers' assessment with the social worker over three meetings and just to be able to discuss my needs and have them recognised by someone was a relief – even if they couldn't meet all my needs."*

*Comment from Carer – "Stroke Survivors – Our Stories, in our Words" Eastern Health and Social Services Board Stroke Strategy Implementation Project*

*"I found the action planning really useful as I have a lot on my plate and tend to run myself into the ground and be exhausted, but now I use my action plans and have more structure to my days and get more done"*

*Response from a carer who participated in the Action Mental Health/Western HSC Trust Long Term Conditions Self Management programme*

- 5.10 Where carers are assessed to have emotional or mental health problems the provision of psychological or counselling support should be made available. Where necessary, opportunities for appropriate respite care, tailored to the needs of the individual and their carer should also be put in place. For younger carers, and as many carers become older themselves, this is particularly important and should be taken into account in planning services. Agreed arrangements for emergency situations should also be in place and known to all relevant parties.

**How can this be achieved?**

- Carers should be offered a needs assessment (NISAT Regional Carer's Support and Needs Assessment Tool for adults and UNOCINI for young carers). Support plans centred on their needs should be developed, monitored and reviewed as required. This includes identifying and addressing any health problems, including mental health problems, experienced by carers.
- With the agreement of the individual being cared for, carers should be respected as partners in planning, improving quality and enhancing the delivery of care.
- Information, advice and support services should be available to carers to support their caring role, including education and training as required.
- Health and social care organisations should liaise with other agencies and services, e.g. benefits, housing, employment, pensions planning, to ensure that carers are able to access appropriate financial and other assistance and support.
- A range of carer support groups should be available and accessible, alongside effective support from health and social care organisations.
- A single point of contact should be identified to co-ordinate services and provide information and support, including knowing where to get help e.g. for dealing with money/benefits.

### **What does success look like?**

Carers are respected as care partners and should, with the agreement of the person cared for, be involved in the planning and delivery of care. Carers are offered a needs assessment (NISAT Regional Carer's Support and Needs Assessment Tool for adults and UNOCINI for young carers). The experiences of carers are improved through access to the integrated and personalised services they need, including respite, to support them in their caring role and sustain their own health and well-being and quality of life.

## CHAPTER 6: IMPROVING CARE AND SERVICES

### Principle

**A pro-active, anticipatory approach should be taken to improve care and services for the management of long term conditions. Services should be person-centred, flexible and integrated across all sectors. Collaborative working should deliver co-ordinated treatment, care and services that are accessible at time of need, maintain or enhance overall health and well-being, support people in their own homes and reduce potentially avoidable admissions to hospital.**

### Background

- 6.1 The increased prevalence of long term conditions is leading to greater demand for health and social care services. Growing complexity, greater numbers of people living with one or more long term conditions and increasing pressure on public funding for health and social care are all driving the need for change in how care and services for people with long term conditions are provided.
- 6.2 In the past, care for people with long term conditions tended to be reactive, generally unplanned and based around hospital care services. In recent years however, the emphasis has been on the development of new ways of managing long term conditions and this has seen a shift to more community-facing, anticipatory care based on multi-disciplinary teams working in partnership with the individual. In response to what people tell us they want, services have been re-focused to maximise the independence of people with long term conditions and help them to develop the skills and confidence needed to manage their condition as part of their lives and reduce their dependence on the more formal and traditional services.
- 6.3 The needs of people with long term conditions extend beyond purely medical intervention, no matter how skilled and vital that may be. How people with long term conditions and their carers manage their condition on

a daily basis can have a huge impact on their quality of life and the progression of the condition. Integrated services, self management training and access to information and to a range of community-based support with and from peers, can make a huge difference to how people cope with their condition.

6.4 The move to more community-based care will require a cultural shift and the development of a range of services which are focused on:

- early diagnosis and intervention;
- crisis response services;
- re-ablement, rehabilitation and intermediate care services;
- telehealth and telecare solutions;
- self care and education for self management;
- support for carers;
- facilitating people to live at home – for example through domiciliary care services;
- respite, particularly emergency respite;
- vocational rehabilitation; and
- equipment and adaptations to support independent living and social inclusion.

6.5 This model of care recognises that with the right level of support, many people with long term conditions can be helped to manage their condition in the community and enjoy a better quality of life. Increasingly people with long term conditions have become key partners in the planning and delivery of services, empowered to take more personal responsibility for their care and supported and encouraged to set realistic goals to maintain and improve their overall health and well-being. For example, for people of working age having a long term condition can affect their ability to work which can cause financial, psychological and social difficulties. A clinically-approved return to the workplace, with agreed goals, phased return and adaptations as required can often offer emotional support and help people regain confidence and capability.



- 6.6 Where people develop more complex or high risk problems, where they are living with more than one long term condition or where they have palliative care needs, a more intensive level of care and support may be needed. In such circumstances case management arrangements will often be required, with a case manager or key worker in place to ensure that care is co-ordinated and integrated and that access to specialist services, support and advice is available.
- 6.7 The HSC Board, the PHA, HSC Trusts and other providers all play a part in ensuring that modern, accessible services are in place to support people with long term conditions, including support services such as respite or domiciliary care.

### **What needs to be done?**

- 6.8 The key to delivering improved care and services is the pro-active and early identification and diagnosis of people with long term conditions. GP practice-based registers can support this by identifying people with long term conditions. The development of minimum information standards should be considered to ensure that there is consistent recording of information about people receiving community care services and to facilitate data sharing. The GP practice register should be the starting point for this.
- 6.9 People with a long term condition should have a holistic needs assessment, facilitated by an appropriate member of the individual's care team. This in turn should inform a personalised care plan. Healthcare services should recognise and, as far as it is safe and appropriate to do so, respond to the individual's preferences for care in line with their assessed needs. In assessing and responding to needs and developing a personalised care plan, the impacts that external determinants such as social deprivation and living conditions may have on an individual's long term condition should be taken into account.
- 6.10 The content and detail of a personal care plan will vary but should usually include the information the individual requires to manage their condition where they are able to do so, including appropriate contact details for

services, advice and support. On the basis of this information, multi-disciplinary teams should work with both the individual and their carer to put in place appropriate care and support services.

- 6.11 Both needs assessments and personalised care plans should be reviewed regularly as needs may change over time, for example when an individual's condition deteriorates or where there are changes in personal circumstances that may impact on care or a person's ability to self manage.

*“Better planning is helping me and hopefully it will see me with less trips to the doctor with stress related sicknesses as I know that's what some of them have been”.*

*Comment from individual who participated in the Action Mental Health/Western HSC Trust Long Term Conditions Self Management programme*

- 6.12 People with long term conditions may need care over many years, during which time they may experience flare-ups and exacerbations which could necessitate moving between different care settings. Where such transitions occur, it is important for the individual that care and services are co-ordinated and do not become fragmented, confusing and overwhelming. Good communication, co-ordination and information sharing within and between multi-disciplinary teams are essential to ensure that where a person moves between different care settings, for example between primary care and specialist services provided in secondary care, these transitions are seamless and co-ordinated.
- 6.13 Care pathways can also facilitate the co-ordination and integration of care by mapping out the services available for the treatment and ongoing support of specific conditions and how the different elements and providers of care are connected.
- 6.14 Where vulnerable patients or those with particularly complex needs, including those with palliative care needs, require a more intensive level of care, case management and specialist clinical support arrangements should be put in place to ensure that such care is available and co-ordinated, including out-of-hours care. Personalised care plans for people with more complex needs should detail anticipatory arrangements for deterioration in

condition or emergency situations. Proper handover arrangements and procedures should also be in place for when a case manager or key worker changes or is off duty for long periods, for example due to illness or leave.

- 6.15 There are a number of examples of services that are being developed to improve care. The roll out of Emergency Care Summary Records aims to improve co-ordination of care through accessible patient information for out-of-hours services, Emergency Departments and hospital pharmacy services. The concept of a patient passport, held by the individual themselves, can also help co-ordinate care across different settings by providing vital personal information which would instantly be of help to health and social care professionals and other agencies.
- 6.16 Direct Payments can also facilitate independent living by offering people the flexibility and choice to purchase the social care services that best support them. Trusts should continue to promote Direct Payments and provide information and support to enable such arrangements to be put in place where appropriate.

#### *Mental health and well-being*

- 6.17 Good mental health is fundamental to a person's overall sense of well-being and quality of life. Mental health issues may be a symptom of a long term condition or a side effect of medication; however being diagnosed with a long term condition can itself have a detrimental effect on the mental and emotional health of individuals and their carers. People with long term conditions are at increased risk of mental health problems, especially depression<sup>21</sup> which occurs in about 20% of people with long term physical illness - two to three times higher than in those who are in good health<sup>22</sup>.
- 6.18 People with long term conditions may therefore often have psychological and emotional health needs, whether or not there is a formal diagnosis of mental health problems or illness. It is important that those working with people with long term conditions are aware of the potential impact on mental health and well-being and are equipped with the knowledge and skills to respond effectively and with sensitivity. Where a person is living with a long term condition, both the needs assessment process and their personal care

plan should be regularly reviewed to consider their mental health and ensure that good psychological well-being is maintained. Assessment should also seek to identify and address the underlying causes of mental ill health.

- 6.19 The benefits of psychological interventions and support in helping people cope with and adjust to physical health conditions, continuing pain, medication adherence, self management, disease progression and palliative and end of life issues should be recognised. In addition to psychological therapies such as counselling for people with anxiety or depression, a range of cohesive and integrated support services, including peer support, should be available to help prevent or to address mental ill health in people with long term conditions.

*Technology, adaptations and equipment*

- 6.20 There is significant scope for new and emerging technologies, equipment and adaptations to make a positive contribution to the care of people with long term conditions and help them maintain or enhance their independence and social inclusion as well as providing reassurance for their carers<sup>\*</sup>.
- 6.21 Telehealth monitoring equipment can be used by people at home to help them self manage their condition allowing them to record their vital signs, manage their symptoms and control their condition more effectively. Technology can also be used by trained staff to monitor an individual's condition remotely. Such systems can give early warning of a dip or deterioration in condition thereby alerting the individual and health and social care professionals to allow earlier interventions which may prevent potentially avoidable admissions to hospital.
- 6.22 Technology can also increase the options and choice available to an individual with a long term condition, for example remote consultations and

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\* In March 2011, HSC Trusts signed a 6 year contract to provide remote telemonitoring services. Patients with heart and respiratory conditions, diabetes and those who have suffered a stroke can have their vital signs, such as pulse, blood pressure and body weight, tested at home on a daily basis and monitored centrally. Care providers will be alerted to any change in their patients' daily readings that might mean a deterioration in their condition, so that they can decide whether an intervention is necessary.

tele-conferencing can minimise disruption by avoiding unnecessary travelling to appointments and improving access to specialists. In addition, a whole range of assistive technology and other support is available to help people to live independently, including sensors and medicines compliance aids, mobility equipment, computer software and other adaptations and equipment for the home or workplace which can help people manage their condition, maintain independence, remain in or rejoin employment and continue living at home.

- 6.23 It is crucial that where technology and equipment are used that the individual and their carer are competent and confident in their use and that the deployment of technology, aids and equipment is only undertaken when it is safe and appropriate to do so and where there are clear benefits to the individual. Caution should also be taken to ensure that using technology does not lead to dependency or over-reliance, especially at the expense of other types of care such as rehabilitation or specialist nursing. Crucially, technology must be used to supplement and not replace face-to-face contact and personal support and the level and extent of its use for and by individuals should be subject to regular review.

#### Workforce planning and development

- 6.24 A skilled, competent and confident workforce is fundamental to ensuring high quality services for people with long term conditions and to support the shift to a more community-based model of care that focuses on anticipatory and preventative services and engages people as partners. The numbers, skill mix and role of the workforce should be developed to ensure that the capacity is in place that will allow specialist and generalist staff in both the secondary and primary sectors, as well as those in the voluntary, community and independent sectors, to meet the current and projected demands on health and social care arising from the increasing prevalence of long term conditions.
- 6.25 New ways of delivering care will require a culture change in how health and social care professionals interact and make decisions in partnership with patients and carers. It is important that the workforce understand and are sensitive to the wider issues and impacts of living with long term conditions -

such as the potential impact on mental health and well-being - and that there is effective joined up working through, for example, multi-disciplinary teams that focus on the overall needs of the individual.

- 6.26 All those working with people with long term conditions should have the skills to motivate and advise them and their carers on good physical and mental health and well-being. Workforce development should include education and training that will help staff acquire the knowledge and competence necessary to plan and deliver new models of care, initiatives and technologies.

### **How can this be achieved?**

- GP practice-based registers should be used to ensure the pro-active and early identification of people with long term conditions.
- Holistic needs assessment should address the overall health and well-being of people with long term conditions and their carers, including their need for physical, psychological and socio-economic support.
- The Northern Ireland Single Assessment Tool (NISAT) should be fully rolled out as the agreed regional tool for all carers, and for older people with long term conditions, and developed as necessary for other groups.
- Person-centred and anticipatory care plans, including contact and/or key worker details, should be in place for those with long term conditions.
- Where appropriate, existing services should be re-shaped to be more accessible, appropriate and effective in line with an assessment of population needs.
- Direct Payments should be maximised to enable people to make their own decisions about how their social care is delivered and how this support is shaped.
- There should be appropriate use of assistive and other new technologies and equipment to support people at home.
- There should be a skilled, competent and confident workforce across all care sectors to facilitate the shift in services from acute to primary and community care.

## **What does success look like?**

People with long term conditions and their carers feel informed about their condition and confident about their health and social care. Services, systems and a skilled and competent workforce are in place to identify and provide the right level of accessible and co-ordinated care and support, at the right time and in the right way, to help people to manage their condition and maintain independence for as long as possible and to reduce potentially avoidable admissions or prolonged stay in hospital.

## THE WAY AHEAD

This policy framework provides a context for the design and delivery of better services for people with long term conditions and their carers. It identifies a number of key development areas which, taken together, will help ensure the provision of high quality care and support for people living with long term conditions. Within each development area, the policy framework outlines what makes for high quality care and what should be done to achieve this.

The Health and Social Care Board and the Public Health Agency have key roles to play in commissioning health and social care services for people with long term conditions within available resources and in line with the good practice outlined in this policy framework. Key to good care will be a partnership approach, with the HSC Board, the PHA and HSC Trusts working together with the independent and voluntary and community sectors – in particular the Long Term Conditions Alliance (Northern Ireland) - to plan, design and implement services based on assessed need.

A Regional Implementation Steering Group will be established by the Department with agreed Terms of Reference to drive forward the development areas and good practice set out in this policy framework and to provide strategic leadership to the reform and modernisation of services for people with long term conditions. The Regional Implementation Steering Group will comprise stakeholders from the statutory, independent and voluntary and community sectors. The Long Term Conditions Alliance (Northern Ireland) will be invited to play a key role on the Implementation Steering Group.

The Regional Implementation Steering Group will develop an action plan identifying how the good practice outlined in the six development areas in the policy framework can be implemented and extended regionally and at a local level, working in partnership with the voluntary, community and independent sectors. The action plan should be in place and approved by the Department within 6 months of the Regional Implementation Steering Group being established.

The Terms of Reference for the Regional Implementation Steering Group will include arrangements for reporting to the Department on progress against the



action plan. These arrangements will include the submission of a formal annual report.

The Primary Care Partnership (PCP) Pathfinder pilot schemes have offered the opportunity to consider how innovative approaches to providing care could be adapted for the management of long term conditions. The objectives underpinning Primary Care Partnerships included the re-design of services across care pathways with improved integration across care settings. “Transforming Your Care” introduced the concept of Integrated Care Partnerships bringing together professionals in primary and secondary care settings to promote the development and improvement of integrated services for patients.

The table in Annex B summarises the good practice set out in the *‘How Can This Be Achieved?’* section for each development area. Taken together, these actions will support high quality care and will contribute to a number of key outcomes including:

- better quality of life for people with long term conditions;
- increased numbers of people able to self manage their condition with support;
- reductions in potentially avoidable hospital admissions;
- improved access to services in the primary and community sector;
- and
- more people able to maintain independence in their own homes for as long as possible.

## Methodology

Following on from the Long Term Conditions workshop held in April 2010, the Department established a Working Group to produce this policy framework. The Group was comprised of representatives of the Department, the Health and Social Care (HSC) Board and Trusts, the Public Health Agency (PHA), the Patient and Client Council (P&CC), the Long Term Conditions Alliance NI (LTCANI), Community Pharmacy NI (formerly the Pharmaceutical Contractors Committee - PCC) and the Royal College of General Practitioners (RCGP). The full membership of the Working Group is set out below.

<b>Member</b>	<b>Organisation</b>
Dr Miriam McCarthy (Chair)	DHSSPS (until May 2011)
Catherine Daly (Chair)	DHSSPS (wef August 2011)
Christine Jendoubi	DHSSPS (until July 2011)
Eugene Rooney	DHSSPS (wef July 2011)
Bernie Redmond	DHSSPS
Dr Martin Donnelly	DHSSPS
Dr Mark Timoney	DHSSPS
Maeve Hully	Patient and Client Council
Dr Sloan Harper	HSC Board
Dr Margaret O'Brien	HSC Board
Eddie Ritson	Public Health Agency (ECCH)
Michelle Tennyson	Public Health Agency
Dr Keith McCollum	RCGP
Donald Moore	Community Pharmacy NI (formerly Pharmaceutical Contractors Committee (NI) Ltd)
Steve McBride	LTCANI
Heather Monteverde	LTCANI
Ian Walters	LTCANI (until December 2010)

David Babington	LTCANI (wef January 20110
Sarah Browne	South Eastern HSC Trust
Gabby Tinsley	Belfast HSC Trust
Angela McVeigh	Southern HSC Trust
Dr Gillian Rankin	Southern HSC Trust
Gene Gillease	Western HSC Trust
Valerie Jackson	Northern HSC Trust
Suzanne Pullins	Northern HSC Trust
Anne Mills	DHSSPS
Gillian Seeds	DHSSPS
Maurice Finlay	DHSSPS (until November 2010)
Karen Dawson	DHSSPS

During the development of this framework a number of additional experts were co-opted to sub-groups.

Richard Dixon	Patient and Client Council
Helen Ferguson	Carers NI/LTCANI
Kate Fleck	Arthritis Care/LTCANI
Melanie McClements	Southern HSC Trust
Janice McCulla	NI Cancer Network
Genevieve Murphy	Macmillan/LTCANI
Jayne Murray	British Heart Foundation
Gayle Nelson	HSC Board
Joan O'Hagan	Asthma UK/LTCANI
Danni Sinclair	NICAN/LTCANI
Tom Sullivan	Chartered Society of Physiotherapists/LTCANI

**Note – some individuals were members of more than one sub group**

The Patient and Client Council and the Long Term Conditions Alliance Northern Ireland also engaged in a pre-consultation exercise with public/voluntary sector and service user groups, the results of which have been fed into the development process. As part of this, responses were sought to five general questions:

1. *What has been good about the services you have received?*

2. *What has been poor about the services you have received? What could have been better?*
3. *Is there anything else which might have made a difference for you?*
4. *What would help you manage your condition better?*
5. *What would your top three priorities be for a Long Term Conditions Strategy?*

Eleven responses were received based on discussions with more than 200 people with long term conditions, including arthritis, asthma, MS, stroke, diabetes, respiratory conditions, lymphodema, spina bifida, Parkinson's and brain tumours.

A number of key themes regularly recurred including the quality of medical care, the importance of information and self management and the value of a contact when things go wrong.

Whilst not an academic study, the exercise provided a good sense of the patient/user perspective and of how patients, service users, and carers experience their condition and the health services which support them.

**SUMMARY OF GOOD PRACTICE ACTIONS**

<b>Working in Partnership</b>
People with long term conditions, and their carers, should have the knowledge and skills to allow them to communicate effectively with health and social care staff.
HSC staff should have the knowledge and skills to communicate effectively with people with long term conditions and recognise and take account of the expertise of the patient in how their condition affects them.
People with long term conditions should have a personalised care plan which recognises the expertise, experience and knowledge of all parties, but particularly the individual themselves. The detail and content of care plans will vary but should be based on full and frank discussion with the individual, or where this is not possible their carers, taking account of their needs, personal circumstances and preferences within available resources. Care plans should identify responsibility for each element of care.
A multi-disciplinary and integrated approach to care planning and provision should be standard in working with individuals with long term conditions and their carers.
Organisations - statutory, voluntary, community and independent - should work together in an integrated way, recognising their differing roles, strengths and expertise to ensure that care which meets individuals' needs is delivered effectively.
Health and social care organisations should work closely with other Government Departments, agencies and organisations, in areas such as benefits, housing and employment to enhance the delivery of integrated services.

<b>Supporting Self Management</b>
The HSC Board in liaison with the PHA, Trusts and, as appropriate, independent, voluntary and community organisations should establish the current baseline of self management support in place in each Trust area.
Commissioners should work to secure the provision of a range of quality assured, and regularly evaluated, rehabilitation, education and training programmes to enable self management.
The HSC Board, PHA and Health and Social Care Trusts should work closely with independent, voluntary and community organisations in the development and delivery of education and training programmes.
Appropriate training should be provided to ensure those delivering self management support have the skills needed to do so.
Innovative use should be made of new technology and equipment to help people to self manage as well as to prompt effective and timely professional intervention.
People with long term conditions should have personalised care plans which include the outcome of needs assessments and the self management arrangements appropriate for them. Care plans should also identify shared responsibility for care, the health and social care professionals responsible for their care, and how and when to get help, particularly out-of-hours. A personalised medicines management plan should be included as part of the personal care plan.
<b>Information to Service Users and Carers</b>
The information needs of people with long term conditions, including their preferences for how information is shared, should be discussed with them as a pre-requisite to developing a personalised care plan. Information provided should be regularly evaluated for its effectiveness in meeting individual need.
Commissioners should include patient information provision in their Service Level Agreements with providers (including the independent and voluntary and community sectors) and through the General Medical Services (GMS) Contract.
The HSC Board, the PHA and HSC Trusts should work closely with the independent, voluntary and community sectors in the development and provision of appropriate information for people with long term conditions and their carers.
HSC organisations should carry out assessments and quality assurance of information provided to patients and carers.
Education and development programmes should be available for all staff engaged in information provision to ensure they have the skills to communicate effectively.
The options for the development of a central HSC information resource, such as a HSC portal, should be explored.
The development of 'information prescriptions' should be considered as part of the support offered to people with a long term condition.

<b>Managing Medicines</b>
People with long term conditions should have their medicines management needs assessed, addressed and regularly reviewed as part of an individualised plan for their medicines régime within their personal care plans.
People with long term conditions should be respected as partners in all aspects of their own medicines management and care planning.
Patients' access to medicines and advice should be improved by involving non-medical prescribers in the delivery of medicines management.
Care pathways and individual care plans should be in place which signpost people to medicines management information and services.
There should be better integration of community pharmacy services within the wider primary care sector and with other partners - community, secondary and social care - to support people with long term conditions in the community.
Remote telemonitoring should be considered to help improve medication compliance.
<b>Carers</b>
Carers should be offered a needs assessment (NISAT Regional Carer's Support and Needs Assessment Tool for adults and UNOCINI for young carers). Support plans centred on their needs should be developed, monitored and reviewed as required. This includes identifying and addressing any health problems, including mental health problems, experienced by carers.
With the agreement of the individual being cared for, carers should be respected as partners in planning, improving quality and enhancing the delivery of care.
Information, advice and support services should be available to carers to support their caring role, including education and training as required.
Health and social care organisations should liaise with other agencies and services, e.g. benefits, housing, employment, pensions planning, to ensure that carers are able to access appropriate financial and other assistance and support.
A range of carer support groups should be available and accessible, alongside effective support from health and social care organisations.
A single point of contact should be identified to co-ordinate services and provide information and support, including knowing where to get help e.g. for dealing with money/benefits.
<b>Improving Care and Services</b>
GP practice-based registers should be used to ensure the pro-active and early identification of people with long term conditions.
Holistic needs assessment should address the overall health and well-being of

people with long term conditions and their carers, including their need for physical, psychological and socio-economic support.
The Northern Ireland Single Assessment Tool (NISAT) should be fully rolled out as the agreed regional tool for all carers, and for older people with long term conditions, and developed as necessary for other groups.
Person-centred and anticipatory care plans, including contact and/or key worker details should be in place for those with long term conditions.
Where appropriate, existing services should be re-shaped to be more accessible, appropriate and effective in line with an assessment of population needs.
Direct Payments should be maximised to enable people to make their own decisions about how their social care is delivered and how this support is shaped.
There should be appropriate use of assistive and other new technologies and equipment to support people at home.
There should be a skilled, competent and confident workforce across all care sectors to facilitate the shift in services from acute to primary and community care.



## Glossary of Terms

Allied Health Professionals	Groups of professionals working in Health and Social Care Services, including for example, physiotherapists, occupational therapists and dietitians.
Care Pathway	The steps in the treatment and care of a patient with a particular condition. Care pathways set out the expected progress of the individual as their condition progresses.
Care Plan	The outcome of a needs assessment. A description of what an individual needs and how these needs will be met. A care plan should reflect the choices made by a person about their care.
Carers	Carers are people who, without payment, provide help and support to a family member or friend who may not be able to manage at home without this help because of frailty, illness or disability.
Commissioning	The process of identifying local health and social care needs, making agreements with service providers to deliver services to meet these needs, and monitoring outcomes. The process of commissioning seeks to improve quality of life and health outcomes for patients and carers.
Direct Payments	Money paid by HSC Trusts that allows individuals to arrange for themselves the social care services required to meet their assessed needs.
Key worker	A named member of a multi-disciplinary team with particular responsibility for co-ordinating care.
Long Term Conditions Alliance NI (LTCANI)	An umbrella body for voluntary and not for profit organisations working with and for people with long term conditions in Northern Ireland.
Multi-disciplinary Team	A group of people from different disciplines who work together to provide and/or improve care for patients with a particular condition. The composition of multi-disciplinary teams will include people from various disciplines (both healthcare and non-healthcare).
Morbidity/Co-morbidity	Applies to illness or disease. The morbidity rate is the incidence of disease in a population over a given period of time. Co-morbidity is where one or more diseases occur in addition to a primary disorder.

NI Single Assessment Tool	A system designed to capture the information required for holistic, person-centred assessment of the health and social care needs of an individual.
Primary Care	Family and community health services and major components of social care which are delivered outside the hospital setting. Primary care will usually be the person's main contact with the HSC e.g. GP, Community Nurse, dentist).
Respite Care	Any activity or service of limited duration designed to provide a break for a dependent person and their carer/family from the usual routine. The activity or service can be provided on a planned or emergency basis in the home or outside the home to meet the needs of either the dependent person or the carer and to sustain the carer in their caring role. The distinctive feature of respite care is that it should be a positive experience for both parties in order to enhance the quality of their lives and to support their relationship.
Secondary Care	Care that is usually provided in a hospital or a particular specialised centre. Secondary care is usually accessed as a result of referral from primary care.
Service Framework	Evidence-based standards to improve health and social care outcomes, reduce inequalities in health and social well-being and improve service access and delivery. Service frameworks set out standards of care that patients, clients, families and carers can expect to receive.

**Abbreviations**

<b>AHPs</b>	<b>Allied Health Professionals</b>
<b>COPD</b>	<b>Chronic Obstructive Pulmonary Disease</b>
<b>DHSSPS</b>	<b>Department of Health, Social Services and Public Safety</b>
<b>GMS</b>	<b>General Medical Services</b>
<b>GP</b>	<b>General Practitioner</b>
<b>HSC</b>	<b>Health and Social Care</b>
<b>LTCANI</b>	<b>Long Term Conditions Alliance Northern Ireland</b>
<b>NHS</b>	<b>National Health Service</b>
<b>NISAT</b>	<b>Northern Ireland Single Assessment Tool</b>
<b>P&amp;CC</b>	<b>Patient and Client Council</b>
<b>PCC</b>	<b>Pharmaceutical Contractors Committee (now Community Pharmacy NI)</b>
<b>PCP</b>	<b>Primary Care Partnerships</b>
<b>PHA</b>	<b>Public Health Agency</b>
<b>PPI</b>	<b>Personal and Public Involvement</b>
<b>RCGP</b>	<b>Royal College of General Practitioners</b>
<b>UNOCINI</b>	<b>Understanding the Needs of Children in Northern Ireland</b>

## References

- <sup>1</sup> Based on definition of chronic disease World Health Organisation available online at [http://www.who.int/topics/chronic\\_diseases/en](http://www.who.int/topics/chronic_diseases/en)
- <sup>2</sup> “*Making Chronic Conditions Count: Hypertension, Stroke, Coronary Heart Disease and Diabetes. A Systematic Approach to Estimating and Forecasting Population Prevalence on the Island of Ireland*”; Institute of Public Health in Ireland (February 2010, Dublin)
- <sup>3</sup> For more information about the Department’s strategy for health prevention and promotion see “*Investing for Health*” (DHSSPS 2002, Belfast)
- <sup>4</sup> Based on outcomes from work undertaken by the Patient and Client Council (NI) and the Long Term Conditions Alliance (NI) as a pre-consultation for this document
- <sup>5</sup> “*Supporting People with Long Term Conditions to Self Care – A guide to developing local strategies and good practice*”; Department of Health, England (February 2006)
- <sup>6</sup> “*A Healthier Future – A Twenty Year Vision for Health and Well-being in Northern Ireland 2005-2025*” (DHSSPS 2005, Belfast)
- <sup>7</sup> “*Caring for People Beyond Tomorrow – A Strategic Framework for the Development of Primary Health and Social Care for Individuals, Families and Communities in Northern Ireland*” (DHSSPS 2005, Belfast)
- <sup>8</sup> “*Improving Stroke Services in Northern Ireland*” (DHSSPS July 2008, Belfast)
- <sup>9</sup> “*Improving the Patient and Client Experience*” (DHSSPS/NI Practice and Education Council/Royal College of Nursing 2008, Belfast)
- <sup>10</sup> “*Living Well- Dying Well – A Palliative and End of Life Care Strategy for Adults in Northern Ireland*” (DHSSPS March 2010, Belfast)
- <sup>11</sup> *Physical and Sensory Disability Strategy and Action Plan* (DHSSPS 2012 Belfast)
- <sup>12</sup> *Service Framework for Cardiovascular Health and Well-being* (DHSSPS 2009) and *Service Framework for Respiratory Health and Well-being* (DHSSPS 2010); *Service Framework for cancer Prevention, Treatment and Care* (DHSSPS 2011)
- <sup>13</sup> *Transforming Your Care – A Review of Health and Social Care in Northern Ireland* (Compton et al 2011 Belfast)
- <sup>14</sup> The definition of carers is that used in “*Caring for Carers – Recognising, Valuing and Supporting the Caring Role*” (DHSSPS 2006, Belfast) i.e. people who, without payment, provide help and support to a family member or friend who may not be able to manage at home without this help because of frailty, disability or illness. Frailty of itself is not a long term condition as defined in this document as it is not a disease. However many frail elderly people will also have one or more chronic conditions and, even where they do not, the needs and rights of their carers are no different. Paid carers provide vital services to people with long term conditions and their carers, and others in the community. For the purposes of this document, they are included within Trust services.
- <sup>15</sup> *Guidance on Strengthening Personal and Public Involvement in Health and Social Care*, Circular HSC (SQSD) 29/07. (DHSSPS 2007 Belfast)
- <sup>16</sup> *An eight-year follow-up of arthritis self-management programme participants* by J Barlow et al, published in *Rheumatology* (November 2008) showed that the self management programme ‘Challenging Arthritis’ helped people in the short and longer-term by improving participants’ self-efficacy (confidence in managing their condition); the continued use of some self-management techniques (such as cognitive symptom management, communication with health professionals and exercise); and improving participants’ psychological well-being helping participants to better manage their condition
- <sup>17</sup> A Challenging Pain programme led by Arthritis Care in 2006/7 and involving 188 participants in Plymouth area found that 12 months after the programme completed the average number of GP visits was for participants reduced by 23% whilst health distress was reduced by 31% (106 respondents to follow-up questionnaire)
- <sup>18</sup> “*Northern Ireland Health and Social Care Strategy for Bereavement Care*” (DHSSPS 2009, Belfast)
- <sup>19</sup> Quoted in “*Long Term Conditions Collaborative – Improving Self Management Support*” NHS Scotland (2009)
- <sup>20</sup> “*More than a Job – Working Carers Evidence from 2001 Census*” Action for Carers and Employers led by Carers UK and Leeds University
- <sup>21</sup> Tylee and Haddad, 2007 referenced in “*Depression in Adults with Long Term Conditions 1:How to identify and assess symptoms*”, *Nursing Times.Net* (7 Dec 2009)
- <sup>22</sup> Egede, 2007 referenced in “*Depression in Adults with Long Term Conditions 1:How to identify and assess symptoms*”, *Nursing Times.Net* (7 Dec 2009)