NHS SCOTLAND

LIVING AND DYING WELL

a national action plan for palliative and end of life care in Scotland

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SCOTTISH GOVERNMENT

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a national action plan for palliative and end of life care in Scotland

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FOREWORD

The *Better Health, Better Care* Action Plan set out a new vision for the NHS in Scotland, describing a new ethos for health in Scotland that sees the Scottish people at the heart of a 'mutual' NHS – where people in Scotland have real involvement, representation and a voice that is heard. We are determined to ensure that patients and carers can become genuine partners in the planning and delivery of care and that we work collaboratively with a broad range of stakeholders including the voluntary sector. Such an approach builds on the fundamental principles of equal access to services on the basis of need and care which is free at the point of access. The future of palliative and end of life care in Scotland reflects all of these dimensions.

It is now possible to predict the progress of many diseases, enabling a planned approach to palliative and end of life care in ways which reflect best practice and which are, as far as is practicable, in accordance with the needs and wishes of patients, carers and their families. Accordingly, our aim is to ensure the delivery of high quality palliative care to everyone in Scotland on the basis of clinical need not diagnosis, and according to established principles of equity and personal dignity.

Living and Dying Well, a national action plan for palliative and end of life care in Scotland, provides the focus and momentum to ensure our strategic priority to improve palliative and end of life care services becomes a practical reality and is applicable to all geographical areas of Scotland. We will continue to work collaboratively with the palliative care community in Scotland, and the voluntary sector in particular, and we will work with patients and carers to ensure that we can accelerate and consolidate the good progress already made. I am aware of the many examples of the excellent work which takes place across Scotland and I am personally committed to ensuring that the Scottish Government provides the leadership necessary to plan and deliver accessible, high quality services on an equitable basis. For the first time we will see the development of a single, comprehensive approach to the provision of palliative care that will be embedded across Scotland.

Nicola Sturgeon

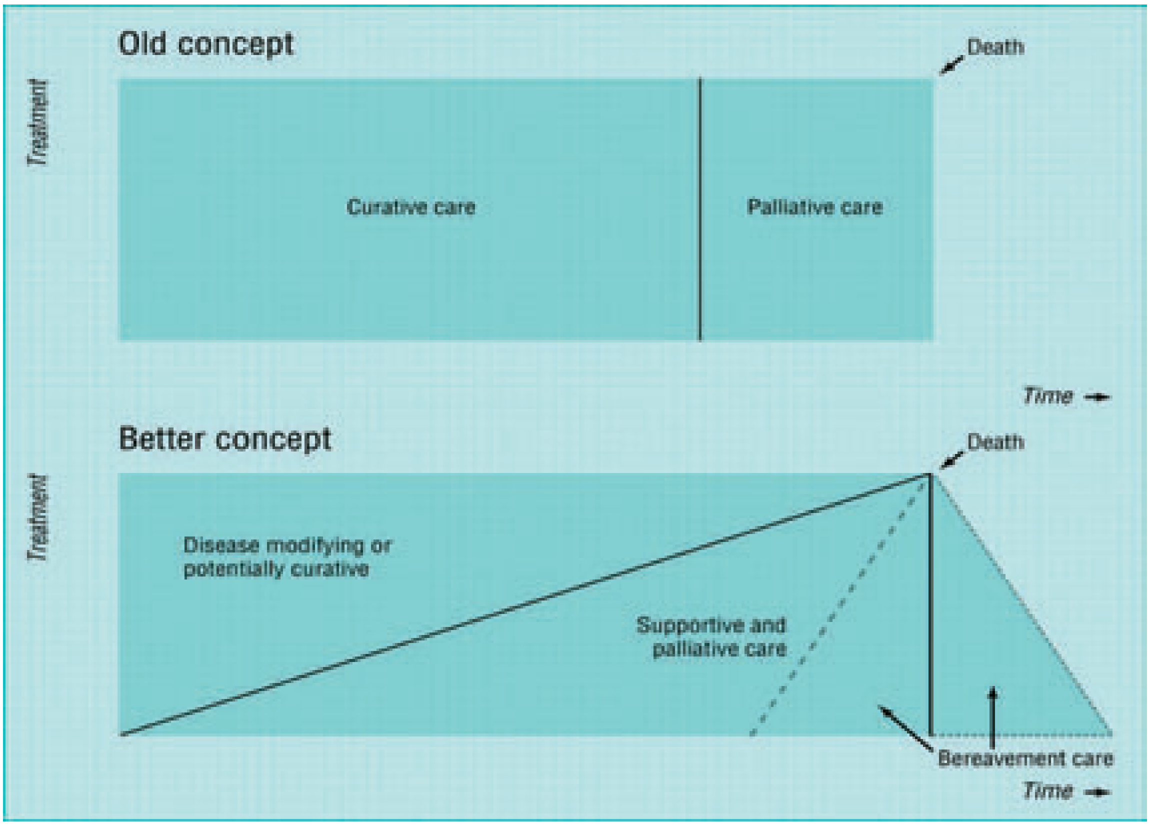
Nicola Sturgeon, MSP
Deputy First Minister and Cabinet Secretary for Health and Wellbeing

1. INTRODUCTION

1. The World Health Organization (WHO) defined palliative care in 2004[1] as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. In 2004 WHO recommended that planning for care at the end of life should be responsive to patient choice regarding place of care and place of death.[2, 3]

2. Palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition. Palliative care is not just about care in the last months, days and hours of a person's life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards. A palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process (See Figure 1). Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement.

Figure 1: Introducing Palliative Care



Murray S, Kendall M, Boyd K and Sheikh A. Illness trajectories and palliative care. BMJ 2005[4]; 330; 1007-1011 doi:10.1136/bmj.330.7498.1007 (adapted from Lynn and Adamson 2003).
Adapted from Lynn and Adamson, 2003.[5] With permission from RAND Corporation, Santa Monica, California, USA.

3. The Scottish Government action plan for health and wellbeing *Better Health, Better Care,*[6] published in December 2007, stated a commitment to the delivery of high quality palliative care to everyone in Scotland who needs it, on the basis of established principles of equity and personal dignity and of clinical need rather than diagnosis. *Better Health, Better Care* also stated the Scottish Government's intention to publish a plan during 2008 introducing for the first time a single, comprehensive approach to the provision of palliative care across Scotland. This plan also provides a basis for implementing the recommendations of the Scottish Partnership for Palliative Care 2007 report *Palliative and end of life care in Scotland: the case for a cohesive approach.*[7] To take this work forward, a National Clinical Lead for Palliative Care was appointed in March 2008 and an Executive Lead has since been identified within each NHS Board.

4. This publication, *Living and Dying Well: a national action plan for palliative and end of life care in Scotland* is the outcome of the resulting extensive process of collaboration across Scotland. This has included the involvement, among others, of all special and territorial NHS Boards, Scottish Government Health and Community Care national improvement programmes, the Scottish Primary Care Cancer Group, the Care Commission, the Scottish Partnership for Palliative Care (SPPC), academic bodies, palliative care networks and key representatives of the voluntary sector, including voluntary hospices, national charities and umbrella bodies. A workshop for key stakeholders, including voluntary sector representatives and all NHS Boards, was held on 3 June 2008. Throughout the process there has been strong support for the aims of the action plan and a shared commitment to planning together to achieve them.

5. *Living and Dying Well* is not intended to be a palliative care manual, but rather a plan to ensure that good palliative and end of life care is available for all patients and families who need it in a consistent, comprehensive, appropriate and equitable manner across all care settings in Scotland. It is intended for all health and social care policy makers, planners and practitioners, and is designed to produce achievable and measurable changes which will ensure quality improvement and enhance patient and carer experience. However, it does not yet have all the answers. *Living and Dying Well* identifies some changes which can be made in the short and medium term, and some which will take a little longer and will require further collaborative and developmental work, as well as additional input of time and resources.

6. *Living and Dying Well* also makes reference to and enables integration with a range of existing Scottish Government policy initiatives and improvement programmes. Its approach supports the development of a mutual NHS as described in *Better Health Better Care* and harnesses the skills, knowledge and experience of initiatives such as:

   - Long Term Conditions Collaborative Programme
   - Scottish Patient Safety Alliance
   - Shifting the Balance of Care
   - Joint Improvement Team
   - Better Together

- Mental Health Collaborative Programme
- eHealth Programme
- Better Cancer Care Strategy
- Rehabilitation Framework.

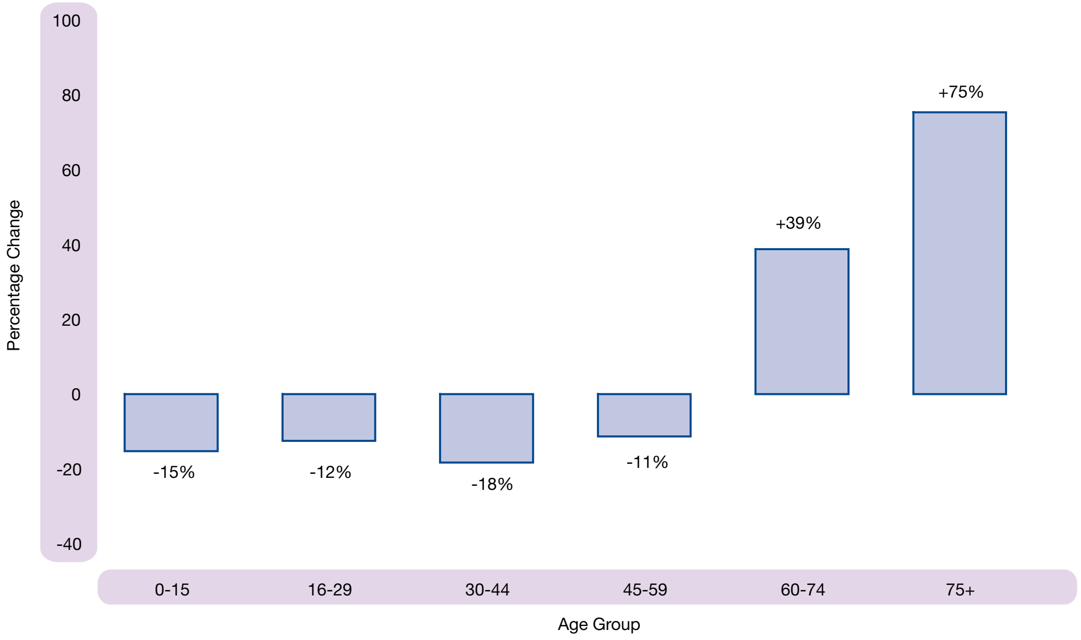
7. In so doing it avoids duplication of effort and resource, enhances collaboration and understanding, and encourages a view of palliative and end of life care as an integral part of healthcare and of the patient experience.

8. *Living and Dying Well* thus represents a cohesive and collaborative approach to the development and maintenance of equitable, high quality and sustainable palliative and end of life care services for the future. It is based on the principles of equality, dignity and quality and supports the national policy of empowering the diversity of patients, carers and the voluntary sector to be full partners in planning, improving quality and enhancing the experience of care. It takes account of the key messages and recommendations in the August 2008 Audit Scotland Review of *Palliative Care Services in Scotland*[8] and advocates an approach to care which is person centred and based on neither diagnosis nor prognosis but on patient and carer needs. It advocates an approach which recognises the diversity of life circumstances of people who will need palliative and end of life care and which is responsive to these circumstances, whether they relate to age, disability, gender, race, religion/belief or sexual orientation[9].

2. BACKGROUND

9. The population of Scotland is ageing. Figure 2 shows the projected percentage change in the age structure of Scotland's population between 2004 and 2031. Figure 3a and Figure 3b show the projected variation in age in Scotland between 1981 and 2031. *Delivering for Health*[10] outlined the implications for Scotland's health and social services of a population living longer, but increasingly likely to be living with a range of long-term and progressive conditions.

Figure 2: The projected percentage change in age structure of Scotland's population, 2004-2031



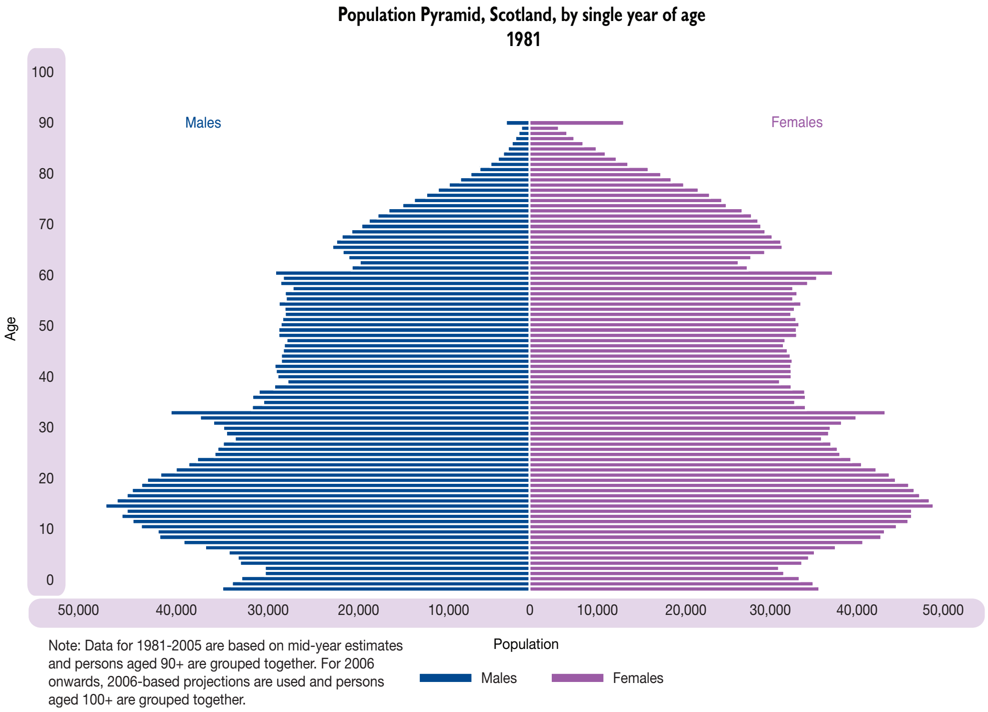
2004-based projections

General Register Office for Scotland. Scotland's Population 2006 - The Registrar General's Annual Review of Demographic Trends

10. Currently over 55,000 people in Scotland die each year.[11] Unlike the past, when many people died suddenly and at any age, largely from infectious diseases, the majority of deaths now are of people over the age of 65 and follow a period, possibly prolonged, of illness and/or frailty. This has wide-reaching implications for the type of care that will be required.

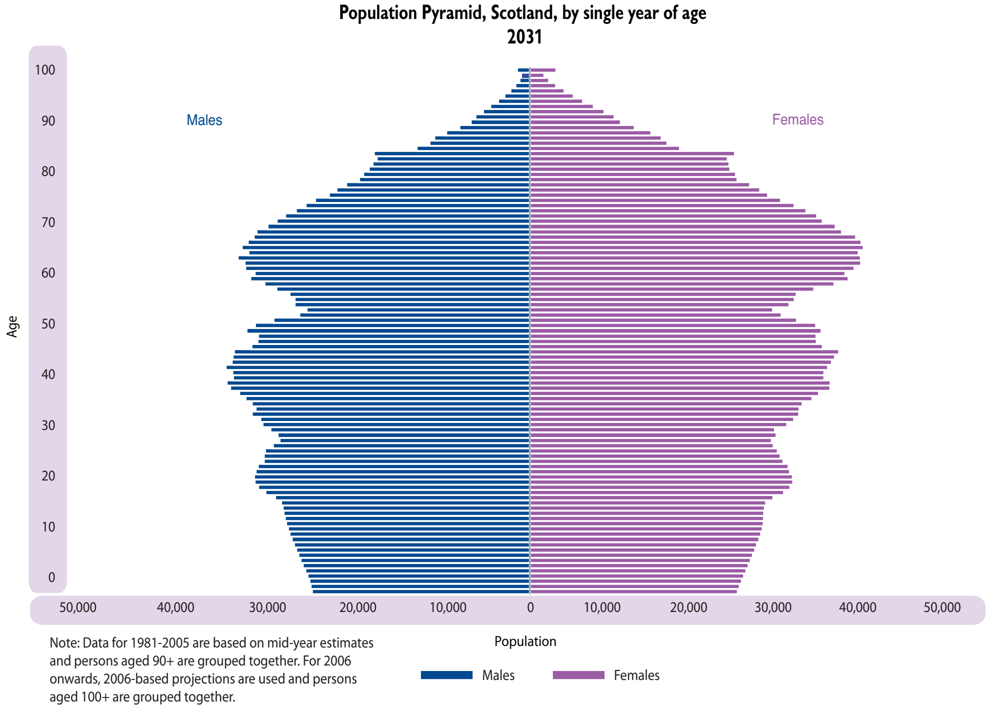
11. Patient and family experiences of death and dying are thought to be affected by the lack of familiarity with such concepts and events in our modern society.[12] Different generations are less likely to live together, and deaths are more likely to happen outwith the family home than in the past. The resulting cultural resistance to acknowledging the reality of death and dying as inevitable and integral parts of life and reluctance to discuss these, particularly in the context of a health service focussed on 'cure' rather than 'care', can contribute to poor communication and planning of end of life care. The SPPC report *Public Awareness of Palliative Care* (2003)[13] indicated that 70% of people in Scotland thought that as a society we do not discuss death and dying enough, and the time is now right to build on this implied willingness to engage with such issues in our service planning and delivery. The Department of Health[12] has announced the development of a national coalition in England and Wales to promote greater public awareness and discussion of issues relating to death and dying, and this action plan will include proposals for exploring these issues in Scotland.

Figure 3a: Population pyramid, actual (1981)



Note: Data for 1981-2005 are based on mid-year estimates and persons aged 90+ are grouped together. For 2006 onwards, 2006-based projections are used and persons aged 100+ are grouped together.

Figure 3b: Population pyramid, projected (2031)



Note: Data for 1981-2005 are based on mid-year estimates and persons aged 90+ are grouped together. For 2006 onwards, 2006-based projections are used and persons aged 100+ are grouped together.

General Register Office for Scotland. Scotland's Population 2006 – The Registrar General's Annual Review of Demographic Trends

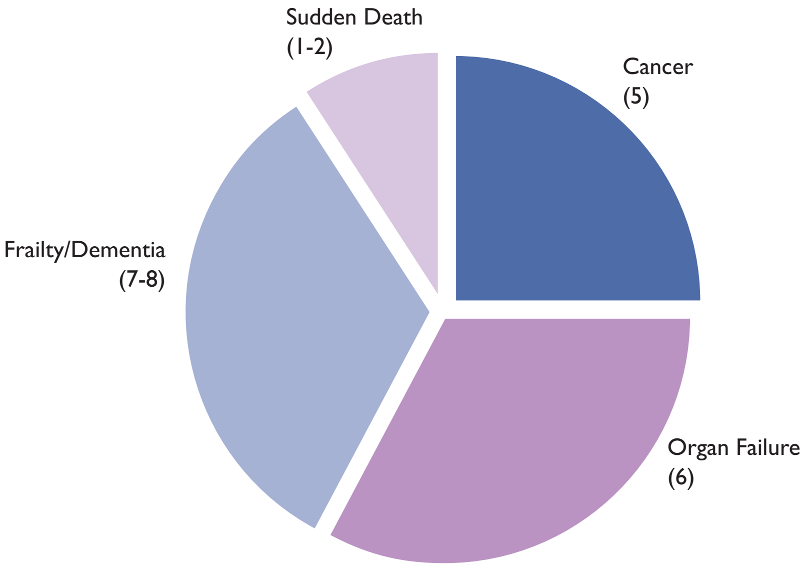
12. Public attitudes to palliative and end of life care should emphasise its availability for all, the adoption of a holistic approach to a range of physical, practical and psychological needs, support for families, and the experience of being treated with respect and dignity.[12,14] The concept of a 'good death' as generally understood also emphasises respect and dignity, underpinned by the exercise of patient and carer preferences and choices and the provision of genuinely patient centred care.[15]

13. The main causes of death in the UK – organ failure, cancer, dementia and/or, frailty – are fairly evenly distributed (See Figure 4). To date, however, the provision of specialist services for palliative and end of life care in Scotland and elsewhere is known to be directed mainly to people with cancer, with a greater range of services available to cancer patients and their families.[7,8] This is partly because the awareness of palliative care needs and the development of specialist palliative care expertise have historically been linked with the needs of cancer patients and with resources for cancer services. Current advances in knowledge and understanding mean that the valuable knowledge and experience gained can now be adapted and shared and people living with and dying from a range of other conditions can benefit from a palliative approach to their care.

14. The concept illustrated in Figure 5 identifies illness trajectories for cancer, organ failure and physical and cognitive frailty which show typical pathways experienced by patients with different conditions. Understanding the differences between these trajectories can help in planning services more appropriately to meet patients' and carers' needs.[4,17,18] Each trajectory indicates a different pattern, indicating periods of relative stability, of intermittent crisis and changing needs and of end of life care needs. The initial diagnosis of a life-limiting condition, together with critical events and changes in disease progression as indicated in the trajectories, should be recognised in all care settings as triggers for the introduction of a palliative care approach and the subsequent stepping up and stepping down to appropriate types and levels of care based on:

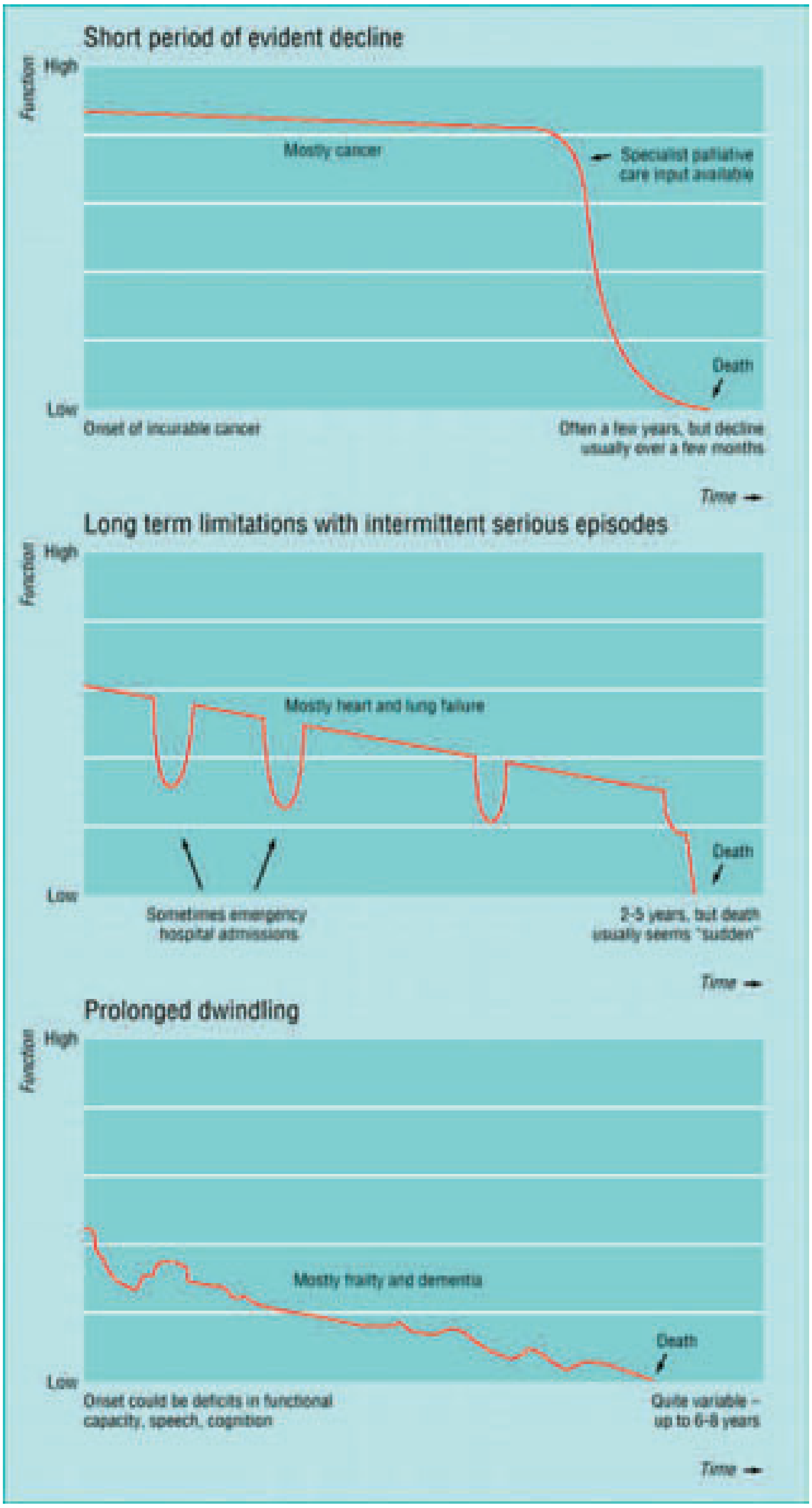
- holistic assessment, with the patient and carer, of their physical, social, emotional, cultural, religious and spiritual care needs and other relevant life circumstances
- planning, coordination and delivery of appropriate care based on the needs identified
- appropriate sharing and communication across all care settings of the needs, and plans identified and actions taken
- regular review and repetition of the assessment and planning cycle.

Figure 4: Average GP's workload – Average 20 Deaths/GP/Year (approximate proportions)



Reproduced with permission from the Gold Standards Framework Centre. Prognostic Indicator Guidance Paper. England 2005: September 2008[16]

Figure 5: Illness trajectories



Murray S, Kendall M, Boyd K and Sheikh A. Illness trajectories and palliative care. BMJ 2005[4]; 330; 1007-1011 doi:10.1136/bmj.330.7498.1007. Reproduced with permission from BMJ Publishing Group Ltd and RAND Corporation, Santa Monica, California, USA

15. This Action Plan uses the concepts of assessment and review, planning and delivery of care, and of communication and information sharing as a framework to support a person centred approach to delivering consistent palliative and end of life care in Scotland. The Action Plan also addresses the need to provide equitable and appropriate access to education and training in palliative and end of life care as well as an infrastructure to support the implementation of the Plan. Each section includes background information and guidance in the form of a narrative, action points and indicative timescales for identified individuals and bodies, and examples of current good practice from across Scotland.

16. A series of short-life working groups will be established to produce recommendations in areas highlighted in the recent collaborative process as requiring future development work. A steering group will also be formed to ensure that the Action Plan is implemented in a pragmatic fashion that recognises local variation in the delivery of palliative and end of life care in each NHS Board area, and yet addresses each of the dimensions of quality outlined in *Better Health Better Care*. Our aim is to ensure that palliative and end of life care in Scotland is of high quality and is continuously improving. Palliative and end of life care will be:

    - patient centred
    - safe
    - effective
    - efficient
    - equitable
    - timely.

3. ACTION PLAN

17. *Living and Dying Well* aims to enable all NHS Boards to plan and develop services which will embed a cohesive and equitable approach to the delivery of palliative and end of life care for patients and families living with and dying from any advanced, progressive or incurable condition across all care settings in Scotland.

18. The key to providing appropriate palliative and end of life care is first of all to identify those likely to benefit from it. An important first step in implementing this Action Plan will be to ensure that triggers for the assessment or review of palliative and end of life care needs are recognised in all care settings at times of diagnosis, at times of changing or complex needs, and at the very end of life. Such triggers include:

- diagnosis of a progressive or life-limiting illness
- critical events or significant deterioration during the disease trajectory indicating the need for a 'change of gear' in clinical management
- significant changes in patient or carer ability to 'cope' indicating the need for additional support
- the 'surprise question' (clinicians would not be surprised if the patient were to die within the next 12 months)
- onset of the end of life phase – 'diagnosing dying'.

3.1 ASSESSMENT AND REVIEW OF PALLIATIVE AND END OF LIFE CARE NEEDS

AIM: To ensure that all patients and carers with palliative and end of life care needs are identified and their physical, social, emotional and spiritual needs are appropriately assessed and reviewed.

19. A theoretical awareness of the three main disease trajectories identified can help with recognition of such triggers. The relatively predictable cancer trajectory of diagnosis, treatment, possible remission and final deterioration is widely understood, and appropriate triggers for assessment and review of cancer patients and their carers already generally recognised. In the organ failure trajectory, critical events such as the frequent unscheduled hospital admissions and readmissions experienced in advanced heart failure or chronic obstructive pulmonary disease (COPD) may be seen as a trigger for further holistic assessment and the development of an appropriate care plan for the next phase of the patient's journey. In the prolonged frailty/dementia trajectory, key events indicating the need for further comprehensive assessment, including consideration of palliative and end of life care needs, might include significant deterioration in function, increased need for carer support, referral for specialist advice, or admission to a care home.

20. 'Diagnosing dying' is seldom easy, but increasing clinical expertise is available in this area[19] and there is increasing awareness that recognition and agreement by the healthcare team that a patient is entering the dying phase allows the planning and implementation of appropriate care.[20]

21. Recognised tools are already in place to facilitate the assessment and review of those with palliative and end of life care needs. These include the use of a palliative care register and prognostic indicators in primary care as introduced by the Gold Standards Framework[21,22] and the use of an integrated care pathway such as the Liverpool Care Pathway for the Dying Patient (LCP)[23] in the last days of life. Use of the Scottish Patients at Risk of Readmission and Admission (SPARRA) risk prediction algorithm to identify patients aged 65 years and over at greatest risk of emergency inpatient admission allows NHS Boards and Community Health Partnerships (CHPs) to identify individuals who would benefit from assessment or review and from co-ordinated care in the community to prevent such admissions. The Single Shared Assessment (SSA), carers' assessment and Indicator of Relative Need (IoRN) are important tools in the holistic assessment of needs required at various stages of the disease process. Guidance on the Minimum Information Standards for Assessment and Care Planning for all Adults has recently been circulated to all local authorities, NHS Boards and Community Health Partnerships.[24,25] The Guidance is supported by developments in education and technology which facilitate the safe and effective sharing of data to support the delivery of person centred care. It is expected that all of these tools, as well as the expertise of specialist palliative care and other specialist teams when required, will be used to ensure that the aim of ensuring appropriate assessment and review is met.

ACTION POINTS

ACTION 1

NHS Boards, through palliative care networks and CHPs, should ensure that recognised tools/triggers to support the identification of palliative and end of life care needs of patients diagnosed with a progressive, life-limiting or incurable condition and the needs of their carers are used across all care settings by 2010.

ACTION 2

NHS Boards, through palliative care networks and CHPs, should ensure that patients identified with palliative and end of life care needs are appropriately assessed and reviewed in all care settings using recognised tools currently available.

ACTION 3

The National Clinical Lead for Palliative Care, in partnership with key stakeholders including diverse patient representation will set up a short-life working group (2008 – 2010) to consider Audit Scotland recommendations regarding standards for palliative and end of life care.

Assessment and review: Examples of good practice

Example 1 – Improving assessment

NHS Forth Valley and the Managed Clinical Network for palliative care have developed a checklist for embarking on end of life treatment (CELT ©). This decision making framework facilitates the transition from active treatment to end of life care and links the Gold Standard Framework and the Liverpool Care Pathway. The CELT framework highlights the importance of excluding reversible causes of decline and can be reused in the event of a further deterioration in the patient's condition.

Example 2 – 'Wider Horizons'

Ardgowan Hospice in Greenock has established an out-patient and drop-in service for patients and carers with palliative care needs. The service provides information, support, education, access to complementary therapies, including cognitive behavioural therapy (CBT) on the basis of assessed need and regardless of diagnosis. Classes are also provided in stress management, relaxation, breathlessness management, yoga, and tai chi. An exercise programme is also available.

The service has provided educational and professional development for staff in the hospice as well as improving working relationships with non malignant services at Inverclyde Royal Infirmary. The service is planning to develop further through projects to support carers at home and to raise public awareness of palliative care.

Example 3 – Full team assessment and review

Staff looking after advanced heart failure patients at the Royal Alexandra Hospital hold weekly multidisciplinary team (MDT) meetings to discuss the management of their patients. The team of staff attending the meetings include representatives from palliative care, cardiology wards, medicine for the elderly, allied health professionals and social work.

The MDT is in its early stages and has initially fostered shared professional learning across disciplines and specialities. The team are planning to work together in developing clinical pathways and management plans to enhance the provision of holistic palliative care.

Example 4 – Macmillan Money Matters

Macmillan Money Matters was established in March 2007 and is a best value service delivery partnership between Macmillan Cancer Support and the three local authorities in Forth Valley, i.e. Stirling, Falkirk and Clackmannanshire Councils. The service has been developed to promote and support the financial wellbeing of all people living with a cancer diagnosis. In its first year the team dealt with 908 referrals, making applications for a number of welfare benefits and other sources of funding. The team has been successful in generating over £2.5 million for clients in that period.

The service is now part of the Scottish wide network of Benefits and Money Advice working in partnership with cancer clinicians to ensure that this significant cause of stress and anxiety for patients and their families is managed effectively. The team offers a wide and varied service, which not only involves making claims and applications for benefits and funds, it also makes referrals to other services that may prove useful to cancer patients and their families.

3.2 PLANNING AND DELIVERY OF CARE FOR PATIENTS WITH PALLIATIVE AND END OF LIFE CARE NEEDS

"The key to caring well for people who will die in the (relatively) near future is to understand how they may die, and then plan appropriately." [4]

AIM: To ensure that care plans are developed and implemented for all patients and carers with palliative and end of life care needs as the outcome of a patient centred planning process which takes account of their needs, wishes and preferences at every stage of the patient journey.

22. Conceptual familiarity with the typical trajectories linked to a range of common diseases has increased our recent understanding of the manner in which we may reach the last phase of our lives. This has provided us with unprecedented opportunities, as planners, health professionals and potential patients, of planning appropriately for that time. The same skills and awareness can and should be brought to bear on planning for appropriate care and support from the point of diagnosis of a life-limiting condition onwards.

23. The Long Term Conditions Collaborative are working in each NHS Board area to implement high impact changes which aim to support patients and carers to be more effectively involved in person centred care planning. These include:

- providing information and education to help people have more control and choice over their care plans
- creating opportunities to explore wishes and choices and help people plan for the future
- embedding Long Term Conditions (LTC) care plans in the Single Shared Assessment process where this is undertaken
- ensuring that the needs of carers are assessed and addressed
- planning ahead for transitions of care including facilitating discussions about preferred place of care
- improving the delivery of pharmaceutical care
- providing telehealth and telecare support
- triggering palliative and end of life care planning.

24. The opportunities presented by this initiative for establishing a cohesive and patient centred approach to the care planning of those with palliative and end of life care needs should be maximized and health and social care professionals in the statutory and voluntary sectors should collaborate to ensure that wherever possible patients' and carers' wishes and preferences are met[24]. The new National Minimum Information Standards for Assessment and Care Planning for all Adults[25] and the User Defined Service Evaluation Tool (UDSET)[26] also support the participation of patients and carers in the preparation and review of holistic, timely and appropriate care and support plans.

25. The Gold Standards Framework (GSF) provides a valuable mechanism in primary and community care for effective patient centred planning during the last 12 months of life. The Framework encourages primary care teams to enhance their knowledge, learning and understanding of palliative care. The Framework relies on effective communication, co-ordination and continuity and emphasises in particular the following aspects of care:

    - identification, assessment and planning
    - individual case discussions and case management by a multidisciplinary team
    - carer assessment and support.

26. This approach should now be extended to ensure that patients with any condition and in any care setting and their carers who have been assessed as having palliative or end of life care needs benefit from the principles and practice exemplified by the GSF.

27. Pro-active care planning and management and early management of symptoms can enhance quality of life for patients and carers and help to prevent crises and unscheduled hospital admissions. This should include the use of anticipatory prescribing, particularly for conditions such as advanced heart failure and COPD where sudden exacerbations are likely, and for end of life medication. Steps should be taken to ensure that patients living in care homes also have access to the benefits of this approach.

28. Future care planning for stages of disease trajectories likely to produce changing patient and carer needs is crucial. Access to additional support and to specialist services, including specialist palliative care, will be required at different stages of the patient journey. Patients on the organ failure trajectory in particular are likely to alternate between periods of stability and potential crisis, and care and support plans should take account of this. Providing appropriate information and allowing adequate time for discussion are important ways of ensuring that patients and carers can explore care and support options with health and social care teams and arrive at informed and realistic decisions.

29. Future planning for end of life care should be included as part of this process, and should include opportunities for discussions about the patient's wishes should he/she become physically or mentally incapacitated in the future[27] as well as about cessation of active treatment, preferred place of care, support for care at home if desired, implementation of an integrated care pathway and the patient's wishes regarding resuscitation. The Scottish Ambulance Service (SAS) and Scottish Partnership for Palliative Care have recently produced a national End of Life Care Plan[28] which will be used by ambulance crews across Scotland and will support a cohesive approach to resuscitation and end of life issues during patient transfer. Advanced care planning with patients and carers will be an important aspect of ensuring the value of this development, as will the adoption by NHS Boards across Scotland of consistent Do Not Attempt Resuscitation (DNAR) policies, such as that developed by NHS Lothian.

30. Care planning should also take account of any religious, cultural, spiritual or other life circumstances that are relevant to appropriate care. In some cases, a person may, during their life time, have given authorisation for the donation of organs after their death. In this case, sensitive discussion should take place with the family. The cultural and religious beliefs of the patient and the family should be respected.

31. The *Shifting the Balance of Care* programme is already addressing the need for adequate support to be available to allow people to be cared for in their own homes at the end of their lives where feasible if that is their and their carers' wish. Implementation of *Living and Dying Well* will support that development, encouraging the provision of practical and emotional support for patients and carers as well as access to 24-hour community nursing for people dying from any advanced progressive condition.

32. Implementation during the last days of life of an integrated care pathway such as the Liverpool Care Pathway facilitates effective planning and provision of care during the dying process. Steps should now be taken to ensure that the LCP or its equivalent is implemented in all care settings for patients dying from any advanced progressive condition.

33. Access to care over 24 hours that meets the needs of patients and carers has been highlighted as a concern.[8] NHS Quality Improvement Scotland (NHS QIS) have recognised the importance of high quality, coordinated care that supports patients and carers with palliative and end of life care needs during the out of hours period. NHS QIS will therefore issue during 2008 Key Performance Indicators (KPIs) for Out of Hours Palliative Care that aim to improve the quality and delivery of palliative and end of life care for patients and carers who access care when their GP practice is closed.

34. As the population ages, care homes are an increasingly important setting for the care of older people with palliative and end of life care needs. National practice statements for general palliative care in adult care homes in Scotland were published jointly by the then Scottish Executive and the Scottish Partnership for Palliative Care in 2006[29] and were used by the Care Commission as part of the inspection focus for care homes from March 2007 – March 2008. Feedback from the inspection process will inform future developments to ensure quality and consistency of care planning and delivery in this sector.

ACTION POINTS

ACTION 4

CHPs, palliative care networks, older peoples services and LTC teams in each NHS Board area should collaborate to ensure that timely, holistic and effective care planning is available for those with palliative and end of life care needs and is carried out in a manner which is person centred and responsive to the needs of the diversity of the population at appropriate stages of the patient journey.

ACTION 5

NHS Boards and CHPs should take steps to ensure that patients with any condition who have been assessed as having palliative or end of life care needs are included in primary care palliative care registers, are supported by a multi-disciplinary team, and have their care and that of their carers co-ordinated by a named health or social care professional.

ACTION 6

NHS Boards and CHPs should take steps, including the use of Patient Group Directions and Just in Case boxes where appropriate, to facilitate the use of anticipatory prescribing to enhance patient care and aid the prevention of unnecessary crises and unscheduled hospital admissions.

ACTION 7

NHS Boards should work collaboratively with local authorities to produce service information directories for use by health and social care professionals and by patients and carers which outline how and when to access the services relevant to those with palliative and end of life care needs, including telemedicine and e-technology. These should be produced in a range of formats and communicated in different ways to ensure they are accessible and appropriate to the diverse needs of all groups.

ACTION 8

NHS Boards should implement consistent DNAR and associated documentation such as the example developed by NHS Lothian across all care settings and provide education to support the effective and appropriate application of the documentation and procedures. NHS Boards should enter into discussion with the Scottish Ambulance Service regarding adoption of DNAR policies which are consistent with the SAS End of Life Care Plan.

ACTION 9

NHS Boards and their partners should ensure equitable, consistent and sustainable access to 24 hour community nursing and home care services to support patients and carers at the end of life where the care plan indicates a wish to be cared for at home and this is compatible with diverse and changing patient and carer needs.

ACTION 10

NHS Boards should ensure that rapid access is available to appropriate equipment required for the care of those wishing to die at home from any advanced progressive condition.

ACTION 11

The Scottish Government will provide support to NHS Boards in ensuring that the LCP or an equivalent integrated care pathway is implemented in all care settings for patients dying from any advanced progressive condition. NHS Boards will be expected to base implementation on delivery plans which address identified education and development needs and link appropriately to quality improvement programmes and expertise.

ACTION 12

Following publication of Key Performance Indicators for Out of Hours Palliative Care by NHS QIS in 2008, NHS Boards should implement and audit these by 2010.

ACTION 13

The National Clinical Lead for Palliative Care will set up a short-life working group in collaboration with the Long Term Condition Alliance Scotland and patient groups representing the diversity of the population to make recommendations on minimum standards for the content of patient and carer information on palliative and end of care.

ACTION 14

The Scottish Government will explore the possibility of using agreed contractual mechanisms to ensure a systematic approach to palliative and end of life care in general practice settings.

ACTION 15

The National Clinical Lead for Palliative Care will liaise with the Care Commission and the Scottish Government to initiate discussions regarding appropriate quality mechanisms such as a review of the National Care Standards. This would allow the Care Commission to take account, during all inspections of adult care homes of the palliative and end of life care needs and process of assessment, care planning and review of all service users, with consideration of their cultural, spiritual and religious needs and other life circumstances.

Planning and delivery of care for patients with palliative and end of life needs:

Examples of good practice

Example 5 – Just In Case (Anticipatory Prescribing Project)

A successful pilot of 'Just in Case' anticipatory prescribing has been undertaken in NHS Highland through the Highland Palliative Care Network. The project aims to provide medication to patients in their own home, to ensure that when symptoms develop immediate and pre-prescribed treatment is available. The provision of the Just in Case boxes has prevented hospital admissions and allows patients the choice to remain at home in their last days of life.

The associated Just in Case guideline and tools provides a safe framework for the use of palliative care medicines in the home as well as an audit trail. Within the initiative a practical tool is used to assist the implementation of the Gold Standards Framework and The Liverpool Care Pathway for the Dying Patient.

The planned roll out, with associated training, will further optimise the skills of Marie Curie and community nurses to respond immediately to patient symptoms.

Example 6 – End of Life – Patient Group Directions (PGDs)

NHS Lanarkshire is in the process of introducing PGDs to allow community nurses, working out of hours, the ability to administer medicines to alleviate common symptoms experienced at the end of life.

PGDs have been developed for medicines to treat confusion/agitation, nausea, anxiety/terminal restlessness and respiratory secretions. Through an education package delivered by a multidisciplinary team including out of hours community co-ordinators, Macmillan Nurses, palliative care pharmacist and the Nursing and Midwifery Practice Development Unit, community nurses will be able to improve the quality of service they provide to patients and carers with palliative care needs.

Example 7 – Marie Curie – Delivering Choice Programme

The Marie Curie Delivering Choice Programme was launched in Tayside in September 2006. The principle outcome of the project is to develop service models that meet the needs of the people in Tayside and focus on:

- achieving effective palliative care within a community setting including hospices
- preventing inappropriate admissions and facilitating discharges to or from hospitals
- improving interface between health and social work including the voluntary sector
- cancer and chronic disease in initial stages.

The Programme is currently in Phase 3 which involves testing and evaluating the service models, concluding with the project handover and the dissemination of findings.

3.3 COMMUNICATION AND CO-ORDINATION

AIM: To ensure that all patients and carers with palliative and end of life care needs are supported to participate fully in developing care plans and making decisions about their care.

To ensure that their needs are communicated clearly across care settings and systems to all professionals involved.

To ensure that the care of all patients and carers with palliative and end of life care needs is co-ordinated effectively between specialties and across care settings and sectors.

35. Communication between professionals and patients/carers is an important aspect of palliative care in any setting. However, effective communication and co-ordination between professionals, especially across organisational boundaries, systems and structures, can play an even more crucial role in ensuring the quality of care and enhancing patient and carer experience.

36. Patients on any of the disease trajectories identified above are likely to move between primary and secondary or tertiary care, and to be cared for by primary care teams, by condition-specific specialists and/or secondary care teams in general medicine or medicine for the elderly and, if their needs are complex, from time to time by palliative care specialists also. The value of identifying a named health or social care professional to plan and co-ordinate care has already been highlighted. Such an individual can also play a key role in ensuring that timely and relevant information is communicated to all other professionals involved, particularly at times of transition from one care setting to another.

37. The transfer of appropriate information between care settings, including out of hours services and NHS 24, could be improved, and is known to have particular significance for those with palliative and end of life care needs. The Scottish Government is therefore facilitating development of an electronic Palliative Care Summary (ePCS) (see Annex B) which is developed from the Gold Standards Framework Scotland project[29] and is based on the Emergency Care Summary. The ePCS will, with patient and carer consent, allow automatic daily updates of information from GP records to a central store, from where they will be available to out of hours services, NHS 24 and Accident and Emergency services. The ePCS is currently being piloted in NHS Grampian, and subject to successful evaluation, will be rolled out nationally from 2009. NHS Quality Improvement Scotland is currently developing National Key Performance Indicators for palliative care which address out of hours issues.

38. In the meantime, the timely sharing of information between primary and secondary care, especially at times of admission and discharge and including transfer between home, care homes and hospitals, remains a challenge to be addressed. The General Medical Council guidance on confidentiality[31,32] identifies good practice for appropriate sharing of clinical information across the care system. The ePCS now provides a helpful framework for identifying the type of information from assessments and care plans which should be shared. NHS Boards will be expected to ensure, by whatever means are locally available, the availability over 24 hours of such information to all relevant professionals.

ACTION POINTS

ACTION 16

NHS Boards should ensure that safe and effective processes, electronic or otherwise, are in place 24/7 to enable the transfer, to all relevant professionals and across sectoral and organisational boundaries of patient information as identified in the ePCS regarding any patient identified as having palliative and end of life care needs and who gives consent.

ACTION 17

The Scottish Government will appoint a clinical lead to take forward the national roll out of the ePCS in 2009.

ACTION 18

The National eHealth Clinical lead will establish a Palliative Care eHealth advisory group to explore mechanisms to encourage and maximise the use of the electronic Palliative Care summary and to identify any further opportunities created by technology and telemedicine to support and enhance palliative and end of life care.

Communication across care settings and systems:

Examples of good practice

Example 8 – A partnership approach to palliative care

Collaboration between ACCORD Hospice and the Royal Alexandra Hospital (RAH) established a joint NHS consultant post in palliative medicine with responsibility for services at both the hospital and the hospice.

The shared funding has enabled the development of a hospital specialist palliative care team to support the RAH including its surgical palliative care bedded unit. The post has also increased consultant services at ACCORD and in the local community. There has been improvement in continuity and communication between patients, carers and clinicians across the hospice, hospital and community interface. The joint post has also facilitated the use of hospice based services, such as the family support team, to hospital inpatients who are unable to be transferred to the hospice.

Example 9 – Joint out-patient clinics

A joint respiratory/palliative care out-patient clinic has been established for patients with advanced lung disease at the Victoria Infirmary in Glasgow. The hypothesis driving this service development was that COPD is a complex systematic disease with a wide variety of physical and psychological affects which can generate complex and challenging symptoms. Such patients require a multidisciplinary approach to their management including access to both general and specialist palliative care.

The clinic aims to combine best respiratory management of patients with optimal symptom management and supportive care. Outcome measures are currently being developed. However all of the 50 patients attending since December 2007 have reported that the clinic has been beneficial to them.

Example 10 – Assessing and planning palliative care needs

NHS Highland Anticipatory Care Project identifies an ‘at risk of admission’ population using primary and secondary care data, called the Casefinder. The anticipatory care team helps assess the needs of patients and their families and plans for appropriate interventions to support them in accessing services to meet those needs.

As a result there has been a quantified reduction in admissions, readmissions and occupied bed days for the 100 patients who have been followed through for the last 8 months. The project has been very well received by patients, carers and staff. Patients are able to plan ahead and carers have found that the open discussion and explanation of facilities and services previously unknown to them has been very valuable. Staff involved reported increased clarity about their roles within existing teams.

3.4 EDUCATION, TRAINING AND WORKFORCE DEVELOPMENT

"Facilitating a good death should be recognised as a core clinical proficiency, as basic as diagnosis and treatment."[17]

AIM: To ensure that all health and social care professionals are equipped with the knowledge, skills, competence and confidence to care for the diversity of patients and families living with and dying from any advanced, progressive or incurable condition.

39. The Scottish Partnership for Palliative Care[7] has already identified the importance of education and training, particularly for generalist staff across care settings, to the achievement of equitable access to high quality palliative and end of life care. Many of the aims and actions identified in this Action Plan cannot be implemented without the prior or parallel implementation of a range of education, training and awareness raising opportunities for different groups of health and social care professionals. Some specialist staff work all or most of the time with those who have palliative or end of life care needs, but health and social care staff in generalist settings will do so either rarely or for only part of the time. However, if the aims of *Living and Dying Well* are to be met and high quality, appropriate palliative and end of life care consistently available across all care settings, all staff will need to be equipped with the appropriate knowledge, skills, competence and confidence.

40. Specialist palliative care practitioners and educationists, particularly those in the voluntary sector, have always played a key role in sharing expertise and providing education and training opportunities for colleagues, and it is expected that this will continue. The sharing of skills and expertise and the opportunity for dialogue and the sharing of educational opportunities between healthcare teams can also greatly enhance competence and confidence. The Scottish Government recognises, however, that a cohesive national approach, together with the availability of additional support, will be required to bring about the developments required. In partnership with NHS Education for Scotland (NES), therefore, the Scottish Government will work to develop an educational infrastructure for palliative care and a national plan for facilitating and delivering education for generalist staff in all settings, including hospitals and care homes, which will support the delivery of improved palliative and end of life care.

ACTION POINTS

ACTION 19

NHS Education for Scotland will develop a national education plan for generalist staff which will facilitate and support the delivery of improved palliative and end-of-life care in all settings and for the diversity of the Scottish population. A national educational project lead and an advisory group including clinical experts and education providers will be appointed to take the work forward.

ACTION 20

To support implementation of this initiative NHS Boards will be asked to nominate a palliative and end of life care education champion to liaise with NES and to facilitate the sharing and spreading of good practice.

ACTION 21

NES will work in partnership with NHS Boards, Palliative Care Networks, Practice Development Units and Quality Improvement Teams to support the managed implementation and expansion of the LCP or equivalent integrated care pathway across all care settings.

Education, training and workforce development:

Examples of good practice

Example 11 – Working in partnership with Care Homes

NHS Forth Valley has an active local Managed Clinical Network (MCN) for palliative care which brings together representatives from all care settings as well as other stakeholders including representation from the private care home sector. The provision of care in care homes is considered in all aspects of the work of the MCN where appropriate. Examples of this work include:

- implementation of the Liverpool Care Pathway in 40% of care homes
- inclusion of care homes in the roll out of the McKinley Syringe pump
- care home use of the NHS Forth Valley palliative care resource pack
- developing bespoke education packages for care homes.

The examples listed above have helped to develop the working relationship between the MCN and these important partners.

Example 12 – Multidisciplinary palliative care education

NHS Greater Glasgow and Clyde aim to further develop a multidisciplinary education workshop to enhance relationships and improve rapport with patients and carers. Recognition that high quality communication is essential for delivering patient centred care and communication requires a good relationship, has prompted the development of a workshop looking at the creation and maintenance of the relationship between patient and healthcare professional.

The aim of the workshop is to create, maintain and improve rapport with patients and in a format that can be delivered to existing multidisciplinary clinical teams in all settings.

Example 13 – Older People's services in Lanarkshire

A Learning and Practice Sub Group of the Older People's Managed Care Network is taking forward a programme of work to build the capability of staff from partner agencies to support the needs of frail older people at key stages of their journey. This work is led by NHS Lanarkshire's Practice Development Unit with local authority training and development partners. The emphasis is on holistic and person centred care which balances rehabilitation and enablement with an anticipatory and palliative approach in the care of frail older people with complex and end of life care needs. This work includes:

- roll out of Liverpool Care Pathway (LCP) within Older People's directorate assessment, rehabilitation and continuing care wards
- Respect and Dignity/CONNECT in Care project in partnership with NHS QIS, NES and the Care Commission to raise awareness, enhance understanding and improve practice around 'caring with dignity'
- Capable Integrated and Fit for the Future: A Multi-professional multi-agency Capability Framework for Intermediate Care and Long Term Conditions
- pharmaceutical care of older people in community settings
- development of a dementia champion programme.

3.5 IMPLEMENTATION AND FUTURE DEVELOPMENTS

AIM: To ensure that the aims of this Action Plan are met in a manner that is sustainable, compatible with quality improvement and patient experience programmes, and based on recognised good practice.

41. The implementation of *Living and Dying Well* integrates with a range of existing Scottish Government policy initiatives and improvement programmes and encourages a view of palliative and end of life care as an integral part of healthcare and of the patient experience. It advocates a co-ordinated approach across care settings, professions and organisations, and requires collaboration with bodies such as the Care Commission, local authorities, charities and voluntary organisations, and others. A strong governance approach is also needed to ensure that the Action Plan is implemented in a manner which maximises benefit and minimises risk.

42. The involvement of patients and carers as genuine partners in the implementation of *Living and Dying Well* is of paramount importance. Networks should ensure that their engagement with patients and carers is representative of the diversity of the population. Networks should also explore and make use of information from *Better Together* and from available qualitative research on palliative and end of life care.[33]

43. To maximise the opportunities of this collaborative approach while at the same time recognising the inevitable complexities of implementation, strong leadership is essential at Scottish Government, NHS Board, Palliative Care Network and CHP level. The recent appointment of a National Clinical Lead for Palliative and End of Life Care and the identification of an Executive Lead for Palliative and End of Life Care in each NHS Board area are significant developments.

44. Further development work will be required before the aims of *Living and Dying Well* can be fully achieved and before some of the Action Points can be adequately progressed or concluded. NHS Boards will require to carry out assessments of their current services and of patient/carer needs in order to develop appropriate delivery plans. This will include the need to undertake equality impact assessments of any revision or change to services and consideration of areas such as provision of respite care and bereavement services.

45. Areas identified for further work within the next two years in order to assist with the development of a truly accessible and cohesive approach to palliative and end of life care across Scotland include:

    - the consideration of Audit Scotland recommendations regarding standards for palliative and end of life care
    - the development of national palliative and end of life guidelines and referral criteria to specialist palliative care services
    - the development of recommendations for assessment tools and advance care plans
    - the development of recommendations on palliative and end of life information for patients and carers

- the development of recommendations on the delivery of palliative and end of life care in acute care settings
- the development of recommendations on appropriate service configurations to meet the needs of adolescents and young adults with palliative and end of life care needs
- the exploration of ideas and issues for addressing palliative and end of life care from a public health and health promotion perspective.

Short-life collaborative working groups will be set up to address these and the other development areas identified in the Action Plan. Each group will be required to carry out ongoing equality impact assessment of its work and recommendations and will report by March 2010.

46. The National Clinical Lead for Palliative Care has been appointed until June 2010. As well as overseeing the work of the short-life working groups and advisory groups identified in *Living and Dying Well*, the National Clinical Lead will, during 2008-2010, continue to consult widely with service planners and providers to identify appropriate and sustainable plans for the future.

47. The Scottish Government believes that, taken together, implementation of all of the action points and initiatives outlined in *Living and Dying Well* will ensure that by June 2010 a cohesive and sustainable approach to the equitable provision of high quality palliative and end of life care will be in place across Scotland for those living with and dying from any advanced, progressive or life-limiting disease.

ACTION POINTS

ACTION 22

The Scottish Government will establish a National Advisory Group, led by the National Clinical Lead for Palliative Care, to support the implementation of *Living and Dying Well* and make recommendations on appropriate evaluation measures.

ACTION 23

The Scottish Government will ensure that governance arrangements are in place to support the implementation of *Living and Dying Well* and to ensure that its integration with other national initiatives is managed appropriately.

ACTION 24

NHS Board Executive Leads will work with Palliative Care Networks, CHPs and Community Planning Partnerships to carry out assessments of their current services and of patient/carer palliative and end of life care needs, and to develop by March 2009 a delivery plan which will ensure that the aims and specific NHS Board action points of *Living and Dying Well* are met. To ensure a cohesive national approach the National Clinical Lead will ensure that opportunities are available for Board Executive Leads to meet together during this process.

Implementation and future developments:

Examples of good practice

Example 14 – Strategic lead for palliative care patients

Within NHS Greater Glasgow and Clyde a dedicated project manager has been employed to provide strategic leadership to enhance palliative care provision for people with non-malignant conditions across all care settings. The recently appointed project manager is currently developing an action plan, mapping current services/developments and establishing effective working relationships.

The key responsibilities of this post include: bringing together key stakeholders, identifying and resolving any issues/gaps in current service provision, developing and implementing the Liverpool Care Pathway and other relevant Integrated Care Pathways and leading on the implementation of educational programmes.

Example 15 – Standards of Care

Minimum standards of care have been developed in NHS Forth Valley for patients in the community with palliative care needs and a limited prognosis. The standards were identified following collaboration with the key stakeholders including acute and community health staff, social work, voluntary sector and patients/carers and are based on the key issues of communication, role responsibility, education, sustainability and management of change.

The standards will support staff in health and social care by providing a framework based on the principles of good palliative care. They have been developed to provide equity of care across CHPs and to provide clear definitions and a common language for communication with patients and carers.

ANNEX A

Gold Standards Framework – Clinical Prognostic Indicator

Trigger 3 – Specific clinical indicators of advanced disease

These clinical prognostic indicators are an attempt to estimate when patients have advanced disease or are in the last year or so of life. These are only indicators and must be interpreted with clinical judgement for each individual patient, but they can help to alert clinicians to the need for extra supportive are. They have been drawn from a number of expert sources from the UK and abroad, and are updated regularly. Some use such indicators routinely, to assess patients' need for palliative/supportive/hospice care. Although these are intrinsically only a very approximate guide to prognosis, these clinical indicators can therefore act as a rough guide to indicate to those in primary care and in secondary services that patients may be in need of palliative / supportive care. Primary care teams may include these patients on their Supportive/palliative care registers and hospital staff may suggest to GPs in discharge letters that such patients are included on the registers, if helpful.

Co-morbidities or other General Predictors of End Stage illness[1 / 2]

Co-morbidity is increasingly the biggest predictive indicator of mortality and morbidity. Also-

- Weight loss - Greater than 10% weight loss over 6 months
- General physical decline
- Serum Albumin < 25 g/l
- Reducing performance status / ECOG/Karnofsky score (KPS) < 50%. Dependence in most activities of daily living(ADLs)

1. Cancer Patients

Cancer[3]

Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis e.g. lung cancer. 'The single most important predictive factor in cancer is performance status and functional ability' – if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less. More exact predictors for cancer patients are available elsewhere on the GSF website.

2. Organ Failure Patients

2.1 Heart Disease - CHF [4]

At least two of the indicators below :-

- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
- Patient thought to be in the last year of life by the care team - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

2.2 Chronic Obstructive Pulmonary Disease – COPD [5]

- Disease assessed to be severe e.g. (FEV1 <30%predicted – with caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria
- MRC grade 4/5 – shortness of breath after 100 meters on the level or confined to house through breathlessness
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression
- >6 weeks of systemic steriods for COPD in the preceding 12 months

2.3 Renal Disease [6]

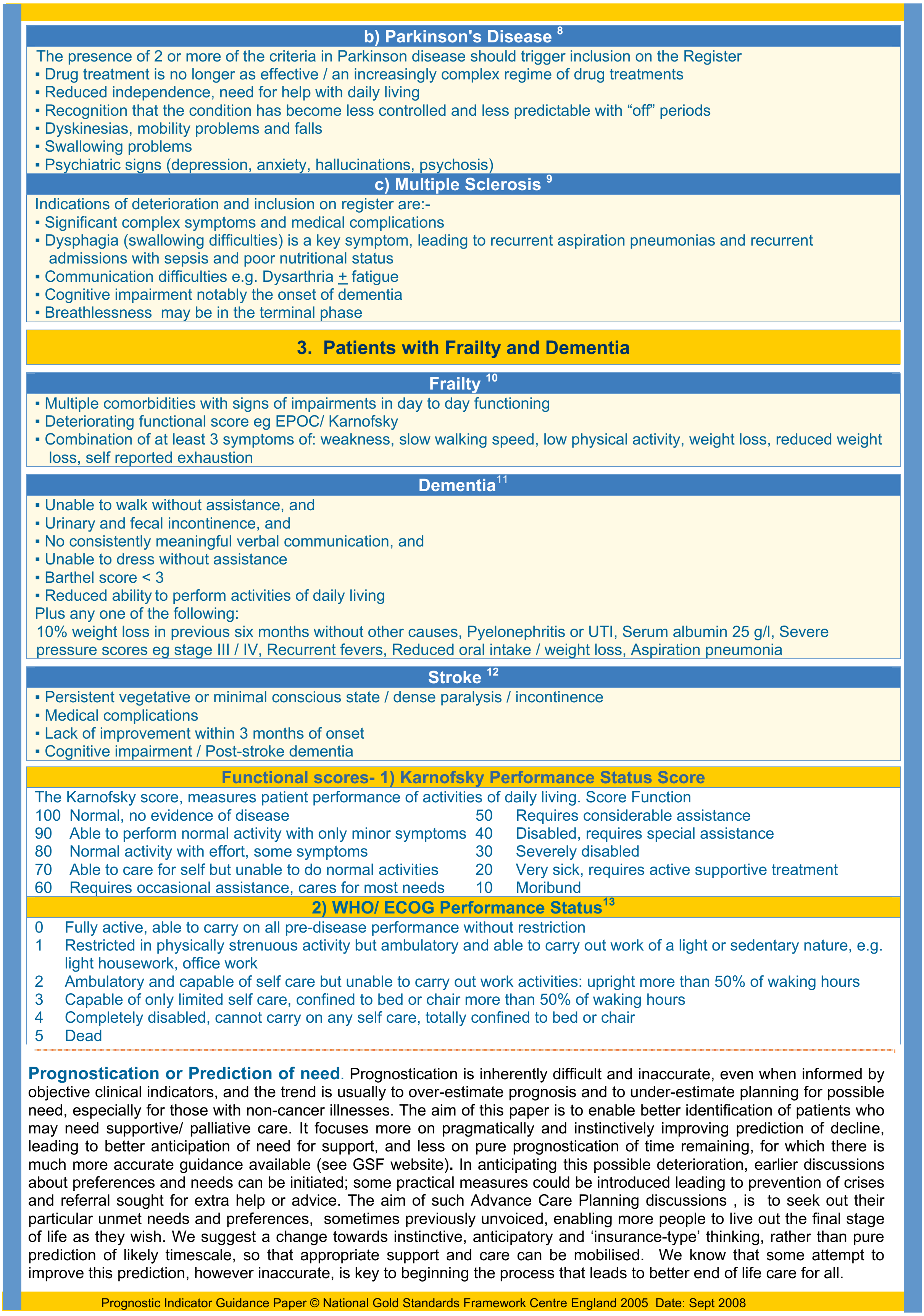
- Patients with stage 5 kidney disease who are not seeking or are discontinuing renal replacement therapy. This may be from choice or because they are too frail or have too many co-morbid conditions.
- Patients with stage 5 chronic kidney disease whose condition is deteriorating and for whom the one year 'surprise question' is applicable ie overall you would not be surprised if they were to die in the next year?
- Clinical indicators:
  - CKD stage 5 (eGFR <15 ml/min)
  - Symptomatic renal failure -Nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload)
- Increasingly severe symptoms from comorbid conditions requiring more complex management or difficult to treat

NB. many people with Stage 5 CKD have stable impaired renal function and do not progress or need RRT.

2.4 Neurological Disease - a) Motor Neurone Disease[7]

MND patients should be included from diagnosis, as it is a rapidly progressing condition
Indicators of rapid deterioration include:

- Evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest
- Barely intelligible speech
- Difficulty swallowing
- Poor nutritional status
- Needing assistance with ADL's
- Medical complications eg pneumonia, sepsis
- A short interval between onset of symptoms and diagnosis
- A low vital capacity (below 70% of predicted using standard spirometry)



b) Parkinson's Disease [8]

The presence of 2 or more of the criteria in Parkinson disease should trigger inclusion on the Register

- Drug treatment is no longer as effective / an increasingly complex regime of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the condition has become less controlled and less predictable with "off" periods
- Dyskinesias, mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

c) Multiple Sclerosis [9]

Indications of deterioration and inclusion on register are:-

- Significant complex symptoms and medical complications
- Dysphagia (swallowing difficulties) is a key symptom, leading to recurrent aspiration pneumonias and recurrent admissions with sepsis and poor nutritional status
- Communication difficulties e.g. Dysarthria ± fatigue
- Cognitive impairment notably the onset of dementia
- Breathlessness may be in the terminal phase

3. Patients with Frailty and Dementia

Frailty [10]

- Multiple comorbidities with signs of impairments in day to day functioning
- Deteriorating functional score eg EPOC/ Karnofsky
- Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, reduced weight loss, self reported exhaustion

Dementia[11]

- Unable to walk without assistance, and
- Urinary and fecal incontinence, and
- No consistently meaningful verbal communication, and
- Unable to dress without assistance
- Barthel score < 3
- Reduced ability to perform activities of daily living

Plus any one of the following:

10% weight loss in previous six months without other causes, Pyelonephritis or UTI, Serum albumin 25 g/l, Severe pressure scores eg stage III / IV, Recurrent fevers, Reduced oral intake / weight loss, Aspiration pneumonia

Stroke [12]

- Persistent vegetative or minimal conscious state / dense paralysis / incontinence
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia

Functional scores- 1) Karnofsky Performance Status Score

The Karnofsky score, measures patient performance of activities of daily living. Score Function

100	Normal, no evidence of disease	50	Requires considerable assistance
90	Able to perform normal activity with only minor symptoms	40	Disabled, requires special assistance
80	Normal activity with effort, some symptoms	30	Severely disabled
70	Able to care for self but unable to do normal activities	20	Very sick, requires active supportive treatment
60	Requires occasional assistance, cares for most needs	10	Moribund

2) WHO/ ECOG Performance Status[13]

0 Fully active, able to carry on all pre-disease performance without restriction
1 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light housework, office work
2 Ambulatory and capable of self care but unable to carry out work activities: upright more than 50% of waking hours
3 Capable of only limited self care, confined to bed or chair more than 50% of waking hours
4 Completely disabled, cannot carry on any self care, totally confined to bed or chair
5 Dead

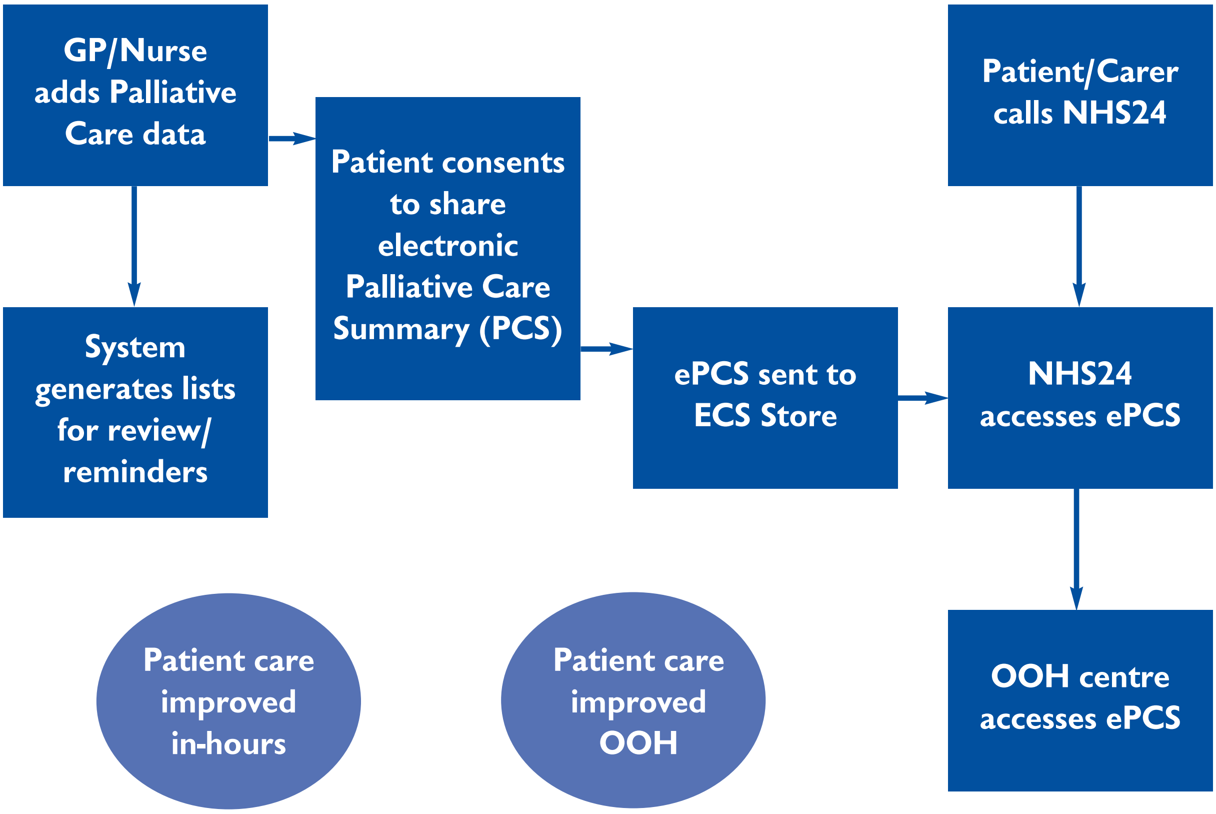
Prognostication or Prediction of need. Prognostication is inherently difficult and inaccurate, even when informed by objective clinical indicators, and the trend is usually to over-estimate prognosis and to under-estimate planning for possible need, especially for those with non-cancer illnesses. The aim of this paper is to enable better identification of patients who may need supportive/ palliative care. It focuses more on pragmatically and instinctively improving prediction of decline, leading to better anticipation of need for support, and less on pure prognostication of time remaining, for which there is much more accurate guidance available (see GSF website). In anticipating this possible deterioration, earlier discussions about preferences and needs can be initiated; some practical measures could be introduced leading to prevention of crises and referral sought for extra help or advice. The aim of such Advance Care Planning discussions , is to seek out their particular unmet needs and preferences, sometimes previously unvoiced, enabling more people to live out the final stage of life as they wish. We suggest a change towards instinctive, anticipatory and 'insurance-type' thinking, rather than pure prediction of likely timescale, so that appropriate support and care can be mobilised. We know that some attempt to improve this prediction, however inaccurate, is key to beginning the process that leads to better end of life care for all.

Prognostic Indicator Guidance Paper © National Gold Standards Framework Centre England 2005 Date: Sept 2008

Reproduced with permission from the Gold Standards Framework Centre. Prognostic Indicator Guidance Paper. England 2005: September 2008[16]

ANNEX B

ePCS Flow Chart



ePCS – Information extracted from GP systems

Date – Updated when sent to ECS	Date – Patient review Date
Patient & Carer Details – Section 1	**Patient's Own GP and Nurse**
Review date	Usual GP name
Patient Surname	Nurse
Patient Forenames	Practice details
CHI Number	
Patient Address & Tel Number	
Carer Details	
Access Info/potential issues	
Next of kin details	
Section 2 Patient medical Condition	
Main diagnoses	
Other relevant issues	
Allergies/Drug reactions	
Current drugs and doses	
Additional drugs available at home	
Section 3 Current Care Arrangements	
Care arrangements	
Syringe driver at home	
Catheter continence prods at home	
Move & Hand equip at home	
Section 4 Patient's and Carer's Awareness of Condition	
Patient's understanding of Diagnosis	
Patient's understanding of Prognosis	
Carer's understanding of Diagnosis	
Carer's understanding of Prognosis	
Section 5 Advice for Out Of Hours Care	
Care Plan agreed	
Preferred place of care	
Should GP be contacted OOH?	
GP Home tel/mobile/pager	
Resuscitation status agreed	
Actual resuscitation status	
GP sign death cert in normal circ?	
Additional useful OOH information	

Gold Standards Framework Scotland – IT Steering Group, 2007.

ANNEX C

Glossary

Advanced Care Plans

The aim of advance care planning is to develop better communication and recording of decisions, thereby leading to provision of care based on the needs and preferences of patients and carers.

Better Together

Better Together is NHSScotland's programme to improve patient experience. It will build upon the improvements already happening across our health service by working with patients, carers and staff to further enhance the quality of care.

The programme will support NHSScotland to make year-on-year improvements for patients and the care they experience.

Care Commission

The Care Commission was set up in April 2002 under the Regulation of Care (Scotland) Act 2001 to regulate all adult, child and independent healthcare services in Scotland. The Care Commission ensures that care service providers meet the Scottish Governments National Care Standards and work to improve the quality of care.

Community Health Partnerships (CHPs)/Community Health and Care Partnerships (CHCPs)

CHPs/CHCPs have been established by NHS Boards as key building blocks in the modernisation of the NHS and joint services, with a vital role in partnership, integration and service redesign. They provide an exciting opportunity for partners to work together to improve the lives of the local communities which they serve.

CHPs provide a focus for the integration between primary care and specialist services and with social care and ensure that local population health improvement is placed at the heart of service planning and delivery.

Community Planning Partnerships

Community Planning Partnerships bring together key participants, and so can act as a 'bridge' to link national and local priorities better. This should be a three-way process whereby local Community Planning partnerships can influence national direction, but also can help to co-ordinate the delivery of national priorities in a way that is sensitive to local needs and circumstances. Local or neighbourhood priorities should also be able to influence the priorities at the Community Planning Partnership level.

eHealth

The eHealth Programme aims to change the way in which information and related technology are used within NHSScotland in order to improve the quality of patient care.

Gold Standards Framework (GSF)

GSF is a framework of strategies, tasks and enabling tools designed to help primary care teams improve the organisation and quality of care for patients in the last stages of life in the community.

Indicator of Relative Need (IoRN)

A standardised tool (currently validated only for use with older people) which groups individuals according to their level of relative need, and is applied following a comprehensive Single Shared Assessment.

Liverpool Care Pathway for the Dying Patient (LCP)

The LCP has been developed to transfer the hospice model of care into other care settings. It is a multiprofessional document which provides an evidence-based framework for end-of-life care. The LCP provides guidance on the different aspects of care required, including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. Additionally, psychological and spiritual care and family support is included.

Long Term Conditions Collaborative

This is a collaborative to support NHSScotland deliver sustainable improvements in patient centred services. The three year national programme will engage all NHS Boards. The focus will be on clinical systems improvement to improve access, reliability, safety and patient experience.

Patient Focus Public Involvement

This is a framework for delivering a culture change in the NHS where patient focus is at the heart of service design and delivery.

Scottish Patients at Risk of Readmission and Admission (SPARRA)

Scottish Patients at Risk of Readmission and Admission (SPARRA) is a risk prediction algorithm, developed by the Information Services Division (ISD) to identify patients aged 65 years and over at greatest risk of emergency inpatient admission and readmission.

Scottish Patient Safety Alliance

The Scottish Patient Safety Alliance has been established to oversee the development of the Scottish Patient Safety Programme. The Scottish Patient Safety Programme aims to steadily improve the safety of hospital care right across the country. This will be achieved using evidence-based tools and techniques to improve the reliability and safety of everyday health care systems and processes.

Shifting the Balance of Care (SBC)

The aim of SBC is to improve the health of the people of Scotland by reducing inequalities and increasing our emphasis on health improvement preventative medicine, more continuous care and support in the community. SBC describes changes at different levels across health and social care – all of which are intended to bring about improvements in health and better service outcomes, providing care which is quicker, more personal and closer to home.

Single Shared Assessment (SSA)

The SSA and Carer's Assessment extend the opportunities to involve a range of staff and agencies in assessment, and stresses the principle that the most appropriate professional should be responsible for carrying out the assessment, co-ordinating any other contributions, and identifying the support or resources needed.

Managed Clinical Networks

A Managed Clinical Network is a network of multi-professional, multidisciplinary and cross-boundary staff (including doctors, pharmacists, nurses, health visitors, physiotherapists and occupational therapists) and organisations from primary, secondary and regional health care working together to make sure that high quality clinically effective services are fairly distributed. Involving patients with experience of the particular illness is an important part of MCNs development.

Mental Health Collaborative Programme

The overall aim of the Mental Health Collaborative is to support NHS Boards to make the improvements needed to deliver against key national targets set out by the Scottish Government.

User Defined Service Evaluation Tool (UDSET)

The User Defined Service Evaluation Toolkit (UDSET) has been developed to enable health and social care partnerships to improve practice through application of user and carer defined outcomes tools, and to gather information from service users and carers on the outcomes that are important to them and use this information for performance management, planning, commissioning and service improvement.

ANNEX D

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ANNEX E

Scottish Partnership for Palliative Care

Extract from Palliative and end of life care in Scotland: the case for a cohesive approach, May 2007

Recommendations

Recommendation 1
NHS Boards and CHPs should encourage adoption of the principles, approach and documentation of the GSFS by the remaining 28% of general practices in Scotland not yet involved.

Recommendation 2
SEHD, NHS Boards, CHPs and palliative care networks should support application of the core principles of the GSFS in all care settings across Scotland.

Recommendation 3
SEHD, NHS Boards, CHPs and palliative care networks should support the ongoing extension of the principles, approach and documentation of the GSFS to patients with life-threatening and long-term conditions and to frail elderly patients with multiple co-morbidities.

Recommendation 4
SEHD, NHS Boards, CHPs and palliative care networks should commit to supporting the ongoing education and facilitation required to allow mainstreaming of the GSFS to be sustainable in all primary care settings.

Recommendation 5
CHPs and palliative care networks should encourage GP practices to make full use of the upgraded IT systems that will become available from summer 2007. This should include GPs using their upgraded existing IT system to record patients' palliative care needs, plan review dates and assist multi-disciplinary team meetings, and sharing summary information with OOH services and NHS 24.

Recommendation 6
SEHD, NHS Boards and palliative care networks should support and facilitate flexible use of the LCP in all care settings.

Recommendation 7
Dedicated resources should be made available by CHPs and NHS Boards to introduce, embed and mainstream use of the LCP across Scotland. This should take into account the need for localisation of LCP documentation to support clinical need, and for appropriate education and training to ensure staff have the necessary understanding to use the LCP successfully and appropriately.

Recommendation 8
All NHS Boards should ensure that systems are in place which allow timely and easy 24-hour access to medication for patients with palliative care needs.

Recommendation 9
Further guidance should be provided to patients and professionals, clarifying when and for what purposes it is appropriate to contact NHS 24, and what information they will be required to provide.

Recommendation 10
Ongoing efforts should be made at a local level to work with NHS 24 to learn from recent experiences to improve services within a local context.

Recommendation 11
All NHS Boards should work towards early implementation of a 24-hour community nursing service to support existing medical OOH arrangements.

Recommendation 12
SEHD should ensure that changes in out of hours provision do not adversely affect the provision or quality of palliative care to patients in the community.

Recommendation 13
The Scottish Executive should conduct an investigation into the implementation of NHS MEL (1996) 22, with a view to clarifying the joint Health Board and Local Authority responsibility for funding palliative and end of life care.

Recommendation 14
NHS Boards, Local Authorities and CHPs should consider adopting/adapting the principles of the NHS Borders model when developing their own approach to joint working and joint care management.

Recommendation 15
The DNAR policy and associated documentation developed by NHS Lothian should be adopted by all NHS Boards, along with education to support the effective and appropriate application of the documentation and procedures.

Recommendation 16
SEHD, NHS Boards and CHPs should make available additional resources to enable appropriate education and training, and to enable dedicated support to facilitate the introduction and sustainability of the improvements outlined in this report.

ANNEX F

Acknowledgements

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