Optimising Older People’s Quality of Life: an Outcomes Framework

Nested models
This report should be cited as:

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2. NHS Ayrshire & Arran
3. Associates of the Joint Improvement Team (JIT)
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Introduction

The outcomes framework is made up of two main components: a strategic outcomes model and four nested logic models that illustrate a range of preventive services areas: food/eating, falls prevention, housing/home environment, palliative care/end of life. These are not a comprehensive set, but were selected to illustrate a range of different service areas that feed into the strategic outcomes necessary for optimising older people’s quality of life. The areas selected were also ones where there were volunteers from the development group who were willing to develop the logic models with a summary of supporting evidence.

Each of the four nested logic models has an accompanying narrative that outlines:

- the current situation/problem in Scotland that the set of actions in the nested model is seeking to improve
- a summary of the evidence for the key actions/interventions in the model
- a series of risks and assumptions that need to be managed (often a common set)
- notes and references.

Each of the four nested logic models shows:

- a series of service-related actions geared to the needs of the key population groups identified in the strategic outcomes model
- the expected results from these actions (short-term outcomes)
- if these results are achieved, the higher-level intermediate and long-term outcomes that are expected to follow (as shown in the strategic model)
- the three types of input or resources required to make these actions happen: older people, their carers and families; collaborating delivery partners and funders; trained staff, equipment, facilities and funding.
1. Older people eat well

Current situation

Malnutrition and undernutrition are important risk factors for older people becoming vulnerable and their independence becoming compromised. Around 1 in 10 people over 65 living in the community are malnourished or at risk of malnutrition. Malnutrition was found to affect 24% of patients admitted to Scottish hospitals in 2007–11, with the proportion of underweight rising steeply over the age of 70 years. Malnourished older people will see their GP twice as often as those who are well nourished, have a threefold risk of hospital admission and their hospital stays will be longer. The direct costs of malnutrition are estimated to range from £5bn for healthcare services to £13bn for associated health and social care services. Preventing underweight in older people living in the community could thus have a substantial effect on reducing hospital admissions and costs.

A wide range of factors have been identified by older people as preventing them from leading a healthy lifestyle and linked to an increased risk of malnutrition: affordability of food, difficulties in accessing food shops, decreased mobility, lack of cooking skills, the impact of major life changes and loss of motivation to eat well.

The focus of this nested model is primarily on outcomes for older people living at home or a home-like setting. Although it recognises the role of health and social care services, it does not cover the detail of secondary health or care home settings. It reflects the key issues, including access and affordability, in relation to older people living at home being able to eat well. The model focuses on ‘eating well’ as opposed to a more narrow focus on diet or healthy eating. The idea of eating well incorporates the avoidance of malnutrition (either undernutrition or obesity), the importance of access to an acceptable and healthy diet and also the wider cultural and social significance of food. Evidence from a number of sources highlights the role that eating with other people can have on appetite and motivation to eat. It also highlights the wider role that food initiatives have in reducing social isolation, building intra/intergenerational and cross-cultural links. The ‘little bit of help’ which food services provide may also include signposting to other forms of support, e.g. handyperson services.

The model reflects the fact that older people’s needs may change over time and that diversity among older people is increasing. In relation to reach, it recognises that particular groups of older people may be at particular risk of not eating well – older men, older people in remote and remote rural communities, older people living with dementia and older people from minority ethnic communities. It also reflects the fact that older people are not solely recipients of services and in many cases are major providers of services. The input that older people provide as volunteers and the opportunities that volunteering provides for increased quality of life are included.

The model also reflects the fact that support for older people to eat well will vary in different parts of the country. Although in some parts of Scotland older people can access a wide range of services to support them to eat well, in other parts the options are more limited. It also recognises that, through coproduction, more innovative and
creative services may be developed to meet emerging needs and expectations. The role of information and advocacy in developing the impetus to address the system change required to address this is covered.

The wide reach of the model means that it is necessarily broad in sweep and it may appear to make some significant leaps.

**Supporting evidence**

Listed below are the main sources used to provide supporting evidence for this model. The evidence base in relation to food, health and older people is growing, but there are, as yet, few large-scale studies or randomised controlled trials on which to draw to demonstrate that eating well is a major determinant of health and wellbeing for older people. Much of the current evidence comes from practitioner reports, case studies and small-scale research.

**National reports**


Local reports


Risks and assumptions

- There is a shared set of values that underpin service development.
- Older people are not a homogenous group and so services may not be equally appropriate or accessible to all.
- Communities have the capacity, resources and assets to engage in these activities.
- The resources, political will and leadership is available to drive the necessary ‘shift in the balance of care’.

Risks

- Healthy-eating messages for older people can be complex and need to be tailored to their particular needs.
- A narrow prevention focus on nutritional supplementation can miss the wider benefits of eating well.
- Persistent stereotypes of ageing (e.g. it is normal to lose weight in old age) can prevent action being taken.
- Lack of leadership and political will to drive change.
- Lack of investment in preventative approaches including community food initiatives.

Other risks and assumptions that are common across all service/programme planning and may need to be managed include:

- Services and service provider staff have the capacity and resources to respond to existing demands and any increased demand. There may be a need for additional staff resource in certain support and service areas if accessibility of services improve and the demand for preventive services increases, or roles are expected to change in response to some of the actions identified in the models. Service providers would need to be adequately staffed and supported in delivering this agenda to ensure effective implementation of the actions and interventions.
- The activities and outputs identified may not deliver the stated outcomes. Services dependent on short-term funding commonly over-claim what changes they will be able to achieve within the timescale of their funding. Using existing effectiveness evidence for similar programmes is the best way to check the plausibility of the claims.
- The service is dependent on the cooperation of other partner agencies (e.g. for referrals). The time taken to build the buy-in and commitment from other delivery
Nested models

partners often delays delivery timetables.

• The service is optimally designed to achieve its goal. Feedback from users and monitoring and evaluation processes are very likely to challenge the way services are currently designed and delivered. The risk of resistance to change needs to be managed.

• The service will reach enough people to make a difference. To achieve the expected level of improvement across a whole population, services often need to obtain a higher level of coverage than is usually planned for and resourced. The risk of low coverage needs to be managed.

• The service is available and effective for everyone. A common assumption made in public services is that the service will reach all those in the population in need. The risk that services are not accessible or tailored to those with the greatest need should be addressed at the planning stage and managed.
Older People Eat Well

CURRENT SITUATION: Malnutrition and under-nutrition is an important risk factor for older people becoming vulnerable and their independence becoming compromised. Food and eating with others has wider social and cultural significance and eating with others can help stimulate motivation, appetite and reduce social isolation. Preventive interventions build on many positive social aspects of food eating as well as addressing some of the main barriers to eating well: the affordability and accessibility of food, decreasing mobility, lack of cooking skills and motivation to eat well, and the impact of major transitions (e.g. bereavement, ill-health).

RISKS AND ASSUMPTIONS

Inputs

- Older people & their families
- Carers
- Friends
- Volunteers
- Policy makers
- Leaders/champions
- Local communities
- Local Authorities
- Schools & Youth groups
- CPPs
- NHS
- Third sector
- Private sector

Activities/Outputs

- Promote information about healthy eating for older people and risks of poor nutrition; knowledge exchange and dialogue
- Community based food initiatives eg: food co-ops, community cafes, cooking classes, community gardens
- Support communities to have capacity to co-produce new innovative asset based approaches and apply locally
- Community based services to help with shopping, food delivery, food preparation, lunch clubs, handyman, transport
- Adaptations/modifications at home to enable safe preparation, storage and eating of food
- Task force to lead advocacy, influence policy, clinical guidelines, innovation, evidence, sharing good practice: older people eating well
- Health and social care services consider older people eating well as part of service provision
- Development of evidence base in relation to older people eating well
- Sharing knowledge, providing opportunities for training and disseminating information and sharing best practice
- Professionals, private, voluntary and third sector service providers

Reach

- Older people who are healthy, active and independent, including carers
- Older people at risk of not eating well eg: men; minority ethnic communities; LGBT; those with long term conditions e.g. dementia. People living in low income, rural and remote rural areas

Short term Outcomes

- Increased awareness and knowledge about key healthy eating messages; improved cooking skills
- More knowledgeable about how/where to access information and support with healthy eating, shopping and cooking
- More involved and engaged as volunteers and in planning, developing and delivering community services
- More opportunities to maintain/build relationships as well as access food
- Better access to appropriate and timely support – a little bit of help is available irrespective of where older people live
- Policies and practice guidelines support older people to eat well
- Improved workforce knowledge and skills around the importance of older people eating well
- Service providers are more skilled in co-producing innovative, creative solutions
- Better understanding of impact/effectiveness of services/initiatives and good practice

Medium term Outcomes

- Physical and social environment is more age friendly
- Improved and more equitable access to affordable food
- Older people are better able to get out and about to grow food, shop for food and eat meals
- Staying/more socially connected
- Food/eating provides a focus for older people:
  - Maintaining friendships and making new social relationships; less socially isolated; more positive and in control
  - Getting involved in their community (e.g. building inter-generational and multi-cultural contacts)
  - Having fun, enjoyment and stimulation
- Keeping/more financially and materially secure
- Welfare system ensures older people have sufficient income for food
- Older people don't have to substitute buying food for other necessities eg: fuel
- More older people are well nourished and flourishing (i.e. motivated to eat and eat well)
- System works better for Older People
  - Food supply/eating is a higher priority in policy and practice
  - Food services for older people are co-produced and more tailored to individual (changing) needs
  - Malnutrition and dehydration are more clearly addressed in health and social care pathways

Resources:

- Staff
- Budget
- Equipment
- Technology
- Buildings
- Contacts and relationships
- Knowledge and expertise
- Research
- Evaluations

CURRENT SITUATION:

Malnutrition and under-nutrition is an important risk factor for older people becoming vulnerable and their independence becoming compromised. Food and eating with others has wider social and cultural significance and eating with others can help stimulate motivation, appetite and reduce social isolation. Preventive interventions build on many positive social aspects of food eating as well as addressing some of the main barriers to eating well: the affordability and accessibility of food, decreasing mobility, lack of cooking skills and motivation to eat well, and the impact of major transitions (e.g. bereavement, ill-health).
2. Falls prevention

Current situation

Falls are a major problem for older people living in the community and a major international public health challenge. More than 30% of people aged over 65 and living in the community fall each year; many fall more than once. In the UK primary care populations the rate rises with age and is generally higher in women and in socioeconomically deprived populations. Falls can cause physical injuries, including fractures and head injuries, psychological harm and longer-term problems such as loss of function, disability, loss of independence and social isolation. Hip fractures are among the most serious fall-related injuries and between 25% and 75% of people who sustain a hip fracture do not recover their pre-fracture function. In Scotland, the cost of falls in older people living in the community has been estimated to be in excess of £471 million per year.

There are a number of modifiable risk factors for falls. These include: environmental and home hazards (e.g. uneven flooring, trip risks such as trailing wires and loose rugs); individual risks (e.g. strength and balance, alcohol consumption, smoking, diet, medication, eyesight and hearing); and existing health problems (e.g. people with poor circulation as a result of diabetes or with weakened bone strength as a result of osteoporosis are more likely to fall and have more serious consequences when they do fall).

Effective interventions

There is consistent evidence that falls interventions have a small to moderate effect in reducing the rate and risk of falls in older people living in a community setting and in institutional care. The strongest evidence relates to the effectiveness and cost-effectiveness of long-term exercise programmes, particularly for high-risk older people (>80 years old). Exercise programmes that appear to have the greatest effect on reducing falls include balance training that contains a higher dose of exercise and does not include walking training. Both home-based and group-based programmes have been shown to prevent falls. Group-based t’ai chi has been found to be effective for falls prevention in several trials.

A review of the cost-effectiveness of falls prevention interventions concluded that long-term exercise programmes are also cost-effective in reducing the rate of falls. The winter use of outdoor walking aids for mobile older people is cost-effective in reducing falls. The best value for money appears to be for single-factor interventions such as the Otago exercise programme which produced cost savings in the higher-risk group of adults over 80 years old. Other programmes that may be cost-effective are multifactorial programmes that target falls risks and home safety programmes for those recently discharged from hospital.

Interventions either have a single-factor focus (e.g. exercise, home safety, medication education, physiotherapy or occupational therapy) or are multi-component (a
combination of assessment and targeted intervention, exercise, falls clinics, physical training, occupational therapy, medication adjustment, advice, environmental assessment). For single interventions, there is no evidence that correction of vision is effective in reducing the number of people falling. There is some evidence (from two randomised controlled trials) that targeting medications may reduce the risk of falls (e.g. withdrawal of psychotropic medicine, educational programmes for family physicians). Overall, vitamin D alone does not appear to be an effective intervention for preventing falls in the general population of older people living in the community, but it may reduce falls risk in women with low vitamin D levels, particularly when combined with calcium, and this intervention may be cost-effective for older women.

No studies have demonstrated a reduction in injuries as a direct result of environmental modification in the home. However, the National Institute for Health and Care Excellence (NICE) (2013) recommend that older people who have received treatment in hospital following a fall should be offered a home hazard assessment and safety intervention/modifications by a suitably trained healthcare professional. Normally this should be part of discharge planning and be carried out within a timescale agreed by the patient or carer and appropriate members of the healthcare team.

There is limited evidence for multifactorial intervention programmes for older people living in the community. Multifactorial assessment followed by targeted intervention appears to be effective in reducing the recurrence of falls, but not the risk of first falls. Multifactorial programmes that rely on referral rather than direct management are less likely to be effective. The success of multifactorial falls-prevention programmes is likely to depend on integration of service delivery working across the community hospital interface and incorporating a range of professional care.

**Falls Prevention Pathway in Scotland**

In Scotland, the ‘Up and About’ pathway describes a four-stage community pathway that spans primary prevention, supported self-management, risk identification and integrated and coordinated management. It is underpinned by tacit knowledge, research findings and recommendations from pertinent guidelines, including those produced by the British Geriatrics Society, Scottish Intercollegiate Guideline Network, the National Institute of Health and Care Excellence and the British Orthopaedics Association.
Since 2010, a network of falls leads from Community Health (and Care) Partnerships have developed pathways locally working with other key stakeholders. The 2012 report, *Up and About or Falling Short*, presented the findings of a mapping exercise in Scotland which aimed to identify the extent to which recommended practices were embedded in systems of care for older people. The report suggested that in recent years there has been progress in the implementation of local care pathways for older people who have fallen, but there remains considerable variation in pathway provision and quality in Scotland.

A framework for action on falls prevention was published in 2014. This builds on the four stages of the *Up and About* pathway and identifies and describes key actions for health and social care services at each of the stages. These actions represent the minimum standard of care an older person should expect to receive, regardless of where and when they present to services.
Risks and Assumptions

The effectiveness of local falls-prevention practice depends on the following assumptions:

- The falls prevention services implemented are high quality.
- Staff are available to deliver falls-prevention services and have appropriate expertise.
- Capacity and systems are in place to record and monitor information on falls.
- Policies are in place to support people to live independently in their own homes for as long as possible.

Further risks and assumptions that are common across all service/programme planning and which may need to be managed for falls prevention include:

- Services and service provider staff have the capacity and resources to respond to existing demands and any increased demand. There may be a need for additional staff resource in certain support and service areas if accessibility of services improves and the demand for preventive services increases, or roles were expected to change in response to some of the actions identified in the models. Service providers would need to be adequately staffed and supported in delivering this agenda to ensure effective implementation of the actions and interventions.
- The activities and outputs identified may not deliver the stated outcomes. Services dependent on short-term funding commonly over-claim what changes they will be able to achieve within the time scale of their funding. Using existing effectiveness evidence for similar programmes is the best way to check the plausibility of the claims.
- The service is dependent on the cooperation of other partner agencies (e.g. for referrals). The time taken to build the buy-in and commitment from other delivery partners often delays delivery timetables.
- The service is optimally designed to achieve its goal. Feedback from users and monitoring and evaluation processes are very likely to challenge the way services are currently designed and delivered. The risk of resistance to change needs to be managed.
- The service will reach enough people to make a difference. To achieve the expected level of improvement across a whole population, services often need to obtain a high level of coverage than is usually planned for and resourced. The risk of low coverage needs to be managed.
- The service is available and effective for everyone. A common assumption made in public services is that the service will reach all those in the population in need. The risk that services are not accessible or tailored to those with the greatest need should be addressed at the planning stage and managed.
Falls Prevention

CURRENT SITUATION: Falls are a major problem for older people living in the community. More than 30% of people over 65 living in the community fall each year and many fall more than once. Falls can cause physical injuries, including fractures and head injuries, and psychological harm along with longer term problems such as loss of function, disability, loss of independence and social isolation. The risk of falling increases with age and is higher in women and in socio-economically deprived populations. Hip fractures are a common consequence of serious falls in the older population and many do not recover their physical function. In Scotland, the cost of falls in older people living in the community has been estimated to exceed £471 million per year.

RISKS AND ASSUMPTIONS
3. Age-friendly homes

Housing and older people’s health and wellbeing

Housing offers essential protection against the environment. In addition, the design, layout and condition of housing and the immediate physical environment affects health and wellbeing, particularly as people get older and spend more time in and around their homes. Achieving changes in this area will involve a generational transformation because of the long-term nature of investment in a built environment that is sustainable.

The housing–health relationship is complex and the nature of causal links between different dimensions of housing and the immediate physical environment can operate at several interrelated levels. Poorly designed or maintained housing exacerbates various existing health conditions and contributes to falls and other injuries and also to preventable respiratory, nervous system and cardiovascular diseases and cancer. In contrast, good housing can limit the effects or incidence of injuries and other health conditions. Physical improvements to the fabric of housing, especially thermal efficiency and central heating improvements, have been shown to contribute to improved respiratory conditions and mental health.

Effective interventions

Enabling older people to remain in their own homes by making adaptations to their existing housing improves the quality of life for the vast majority of recipients, their carers and other family members. It also generates considerable savings for health and social care by preventing, reducing or removing the need for spending on residential care, health care and home care. In Scotland, housing adaptations for sheltered and very sheltered (or extra care) housing tenants have been shown to generate a potential return on investment of £5.50 to £6.00 for every £1 invested, with the Scottish Government recouping £3.50 to £4.00 for every £1 it invests, mainly through savings in care-home costs.

The construction of specialist housing for older people has also been found to produce net annual savings to the public purse of around £400 per person, mainly as a consequence of reducing reliance on health and social care services. Compared with residential care homes, the provision of ExtraCare housing schemes has also been shown to deliver better outcomes for older people needing care, greater cost-effectiveness and the same or lower costs, and the residents had considerably lower rates of mortality. In Scotland, there is also some limited evidence that extra care/very sheltered housing provision delivers superior wellbeing benefits for tenants compared with care homes.

The potential of telecare and assistive technology to extend older people’s independence has been demonstrated by the Scottish telecare development programme 2006–11, with significant potential for savings for healthcare. Telecare also has positive impacts and can reduce patient mortality, reduce the need for hospital admissions and lower the number of bed days spent in hospital.
Older people’s independence and wellbeing can also be supported through the restructuring of the built environment of neighbourhoods and neighbourhood services.\textsuperscript{20,21} Neighbourhoods that are clean, safe places to live and provide the capacity to access health and other services/facilities give older people the confidence and capacity to continue to live independently, maintain their social networks and participate in the wider community.

High-quality, well-lit and inviting pedestrian areas with ample seating and good signage are also important in terms of lowering the risk of falls and making it easier for those with respiratory or mobility problems, wheelchair users and people with dementia to move around outside their home and/or access local facilities.

**Risks and assumptions**

Achieving the outcomes outlined in this nested model requires:

- Explicit national and local political commitment at the highest levels to multi-sectoral structures and processes to manage change.
- Communities being given the skills and time to advise on what development is required locally to help inform and shape the creation of healthier places.
- A clear presumption within the National Planning Framework in favour of sustainable development that facilitates healthy and active living, especially in old age.
- A clear focus on population ageing and health inequalities when planning local urban and rural areas.
- Revisions to the scope of guidelines and regulations surrounding the construction of homes and the design of residential areas (provision of pavements and road crossings, etc.) in support of ageing.
- Buy in and cooperation of private developers to develop age-friendly dwellings.

Other risks and assumptions that are common across all service/programme planning include:

- Services and service provider staff have the capacity and resources to respond to existing demands and any increased demand. There may be a need for additional staff resource in certain support and service areas if accessibility of services improves and the demand for preventive services increases, or roles are expected to change in response to some of the actions identified in the models. Service providers would need to be adequately staffed and supported in delivering this agenda to ensure effective implementation of the actions and interventions.
- The activities and outputs identified may not deliver the stated outcomes. Services dependent on short-term funding commonly over-claim what changes they will be able to achieve within the timescale of their funding. Using existing effectiveness evidence for similar programmes is the best way to check the plausibility of the claims.
- The service is dependent on the cooperation of other partner agencies (e.g. for referrals). The time taken to build the buy-in and commitment from other delivery partners often delays delivery timetables.
• The service is optimally designed to achieve its goal. Feedback from users and monitoring and evaluation processes is very likely to challenge the way services are currently designed and delivered. The risk of resistance to change needs to be managed.

• The service will reach enough people to make a difference. To achieve the expected level of improvement across a whole population, services often need to obtain a higher level of coverage than is usually planned for and resourced. The risk of low coverage needs to be managed.

• The service is available and effective for everyone. A common assumption made in public services is that the service will reach all those in the population in need. The risk that services are not accessible or tailored to those with the greatest need should be addressed at the planning stage and managed.
Age-Friendly Homes

CURRENT SITUATION: As people get older and spend more time in and around their home, housing is not only essential protection against the environment, but the house and its immediate environment becomes more closely connected to maintaining independence and health and wellbeing. Good housing can limit the effects or incidence of injuries and other health conditions. Physical improvements to the fabric of housing, especially thermal efficiency and central heating improvements have been shown to contribute to improved respiratory conditions and mental health. Making adaptations to existing housing can help extend people’s ability to live independently in their own homes. The construction of specialist housing for older people can help reduce reliance on health and social care services and contribute to a greater sense of wellbeing. Older people’s independence and well-being can also be supported through the re-structuring of the built environment of neighbourhoods and community services.

Inputs

- Older people & their families
- Carers
- Friends
- Volunteers

Activities/Outputs

- Information and advice about housing options, services, grant availability, equity release, welfare advice
- Community-run housing and residents’ associations and co-ops – active involvement of residents and volunteers in housing provision and services
- Standards for new housebuilding – Lifetime Home standards
- Quality standards for housing and maintenance – housing is safe, warm, regularly repaired, kept in good decorative order, well insulated, adequately ventilated, energy efficient, suitable security and safety measures (smoke detectors, handrails, outdoor lighting)
- Quality standards for physical infrastructure – accessible buildings (community centres, churches, halls, etc.) for community meetings, self-help; public transport routes well connected to key destinations (e.g. health centres, shops); access to broadband and mobile technology; delivery and provision of mobile shopping and other services by private and social enterprise
- Quality standards for place/Neighbourhoods – pleasant, walkable, well lit, safe, ample seating, good signage, pavement clear of obstructions, low kerbs for wheelchairs, pedestrian crossings, etc.; to assist safe road crossing, well maintained green spaces (parks, allotments, etc.)
- Housing modifications to adapt to needs of older people – equipment, adaptations, technology, access, stairs
- Age-specialist homes – expansions of sheltered housing, co-housing, extra-care housing, care homes
- Senior integration – health, social care, financial and housing services work together to improve early identification of at-risk individuals, inter-agency referrals and service accessibility

Reach

- ALL older people
- Older people who are at risk including carers
- Older people who have high support needs, including carers

Short term Outcomes

- People are better informed about housing options/choices and the services available to help them so that they remain active and independent
- Housing matches housing needs so more older people live in warm safe home environment
- Housing and places are designed so that it’s easier to get out and about and more social and service interaction
- Equity of access to services, communications and infrastructure regardless of age, area of residence
- Residents take more pride in their homes; homes are better looked after; less complaints, happier residents; lower turnover in residents
- Greater involvement and ownership in local housing plans and decisions
- People with disabilities/declining health are more able to move around their homes freely and use facilities in all rooms
- More streamlined, rapid and effective joint decision-making

Medium term Outcomes

- Physical environment is more age-friendly
- Housing located in places that are easy to navigate, pleasant and welcoming
- Neighbourhoods become cleaner, safer environments to live
- Housing designs and choices meet a range of needs, aspirations and financial circumstances
- Transport and social opportunities accessible for older people in social housing
- Healthy and active ageing
- Older people stay positive and in control of their own lives
- Older people are more able to participate in decision-making about their own lives
- Systems work better for older people
- More investment in upstream prevention
- Greater capital investment in improving housing and neighbourhood standards
- Less demand for services dealing with problems

RISKS AND ASSUMPTIONS

- Maintain/improve physical health and function
- More positive outlook, feel safe in their homes and a valued part of community
- More able to live independently for longer with support as required
- Less demand for services dealing with problems
- More positive outlook, feel safe in their homes and a valued part of community
- More able to live independently for longer with support as required
4. Optimising the quality of end of life

Current situation

Each year around 55,000 people in Scotland die\textsuperscript{22} and around 220,000 people are bereaved.\textsuperscript{8} 70\% of these deaths are people aged over 70 years\textsuperscript{23} and death is frequently preceded by a period of declining health. As the size of the older population increases, the numbers of people dying are expected to rise by 17\%.\textsuperscript{24} Around half of all deaths currently occur in hospital.\textsuperscript{25}

The experience of decline, death and bereavement is a central feature of later life and thus optimising the quality of the end of life is an important part of the Reshaping Care for Older People (RCOP) policy and one of the major responsibilities of the health and social care system.

This nested model is focused on activities currently underway in Scotland aimed at improving people’s experiences as they approach the end of life. It does not explore what gaps exist and what additional activities might be necessary to achieve the long-term outcome of optimising the quality of end of life.

What’s needed and effective in optimising the quality of end of life?

Conventional approaches to improving end-of-life care have focused on activities aimed at influencing the health and social care infrastructure, for example training staff, providing guidance and introducing systems and processes designed to improve care. However, this outcomes chain is also based on the growing awareness\textsuperscript{26,27} that people’s experience of death, dying and bereavement is only partially determined in their interaction with traditional formal services, and that social and cultural influences are limiting factors in service improvement. In particular, it explores the possible effects of promoting more openness and knowledge about end-of-life issues, as these are factors which currently restrict people’s ability to plan for and support each other with decline, death, dying and bereavement.

\textsuperscript{8} A figure often used by the Grief and Bereavement Hub, which estimates the number of people bereaved by multiplying the number of people dying by four.
Advance Care Planning

Planning for an expected change in condition is called Anticipatory Care Planning. This should also include consideration of the wider issues involved in Advance Care Planning such as the financial, legal and practical consequences of illness and death.

A study by Baker et al found that the use of Anticipatory Care Planning produced statistically significant reductions in unplanned hospitalisation for a cohort of patients with multiple morbidities. The study concluded that this ‘demonstrates the potential for providing better care for patients as well as better value for health and social care services. It is of particular benefit in managing end-of-life care.’

Early identification of people who need palliative care is important in ensuring that people get the care they need at the right time. A recent study found that most non-cancer patients were identified as requiring palliative care too late to fully benefit – on average only eight weeks before dying. A palliative care approach should be used as appropriate alongside active disease management from an early stage in a disease process.

Social/cultural influences on quality of end of life

Over recent years there has been growing acceptance that the quality of people’s death, dying and bereavement experiences can be improved by creating more cultural openness about these issues. This was central to the establishment of the Dying Matters coalition in England in 2009 by the National Council for Palliative Care. The Scottish Government palliative and end-of-life care action plan, Living and Dying Well, recognised that patient and family experiences of death and dying are affected by a lack of familiarity with death in modern society. Consequently, a short life working group (known as SLWG7) was set up to address ‘the exploration of ideas and issues for addressing palliative and end of life care from a public health and health promotion perspective’. SLWG7 made ten recommendations aimed at raising public awareness and promoting community involvement in the issues of death, dying and bereavement. In January 2011 the Living and Dying Well: Building on Progress report was published by the Scottish Government and recommended the setting up of a broad-based coalition (Good Life, Good Death, Good Grief) to take forward the recommendations of SLWG7 (Action 12).

Risks and assumptions

Risks and assumptions that are common across all service/programme planning and need to be managed include:

- Services and service provider staff have the capacity and resources to respond to existing demands and any increased demand. There may be a need for additional staff resource in certain support and service areas if accessibility of services improves and the demand for preventive services increases, or if roles were expected to change in response to some of the actions identified in the models. Service providers would need to be adequately staffed and supported in delivering this agenda to
ensure effective implementation of the actions and interventions.

- The activities and outputs identified may not deliver the stated outcomes. Services dependent on short-term funding commonly over-claim what changes they will be able to achieve within the timescale of their funding. Using existing effectiveness evidence for similar programmes is the best way to check the plausibility of the claims.

- The service is dependent on the cooperation of other partner agencies (e.g. for referrals). The time taken to build the buy-in and commitment from other delivery partners often delays delivery timetables.

- The service is optimally designed to achieve its goal. Feedback from users and monitoring and evaluation processes are very likely to challenge the way services are currently designed and delivered. The risk of resistance to change needs to be managed.

- The service will reach enough people to make a difference. To achieve the expected level of improvement across a whole population, services often need to obtain a higher level of coverage than is usually planned for and resourced. The risk of low coverage needs to be managed.

- The service is available and effective for everyone. A common assumption made in public services is that the service will reach all those in the population in need. The risk that services are not accessible or tailored to those with the greatest need should be addressed at the planning stage and managed.

**Further reading**

Publications which reference the value of health-promoting palliative care and more openness about death, dying and bereavement are listed below.


Paul S, Salnow L. Public health approaches to end-of-life care in the UK: an online survey of palliative care services. *BMJ Supportive & Palliative Care* 2013;3(2):196–9. (Indicates that public health approaches to death, dying and loss are a current priority for around 60% of hospices, concluding that these findings demonstrate the relevance of a public health approach for palliative care services and how they are currently engaging with the communities they serve.)


*Good Life, Good Death, Good Grief.* [www.goodlifedeathgrief.org.uk/content/experts/](http://www.goodlifedeathgrief.org.uk/content/experts/) (accessed 11 August 2014). The website quotes several extracts from publications putting forward the view that social/cultural factors are important in improving end-of-life care.
References


Optimising Quality of End of Life

CURRENT SITUATION: Around 55,000 people in Scotland die each year, 70% of these are among people aged over 70 years and half currently die in hospital. Around 220,000 people each year are bereaved. The experience of decline, death and bereavement is a central feature of later life and thus optimising the quality of the end of life is an important part of Reshaping Care for Older People. To date this has been focused on influencing health and social care infrastructure and introducing systems and processes designed to improve palliative care. But service improvement is constrained by wider social and cultural taboos against addressing decline, death, dying and bereavement and planning ahead for a good death.

Inputs
- Older people & their families
- Carers
- Friends
- Volunteers
- Health and social care professionals
- Businesses (funeral industry, care homes, legal & financial advisors)
- Spiritual, Religious & Arts organisations
- Scottish Government policy makers
- Leaders/ champions
- Local communities
- Local Authorities
- CPNs
- NHS
- Third sector

Resources: Staff
- Budget
- Equipment
- Technology
- Buildings
- Contacts and relationships
- Knowledge and expertise
- Research
- Evaluations

Activities/ Outputs
- Active promotion of more openness, and dialogue about death, dying and bereavement including in public policy
- Information and advice provided about end of life issues to encourage advance planning – financial, medical, legal and spiritual arrangements e.g. Power of Attorney, Wills, Advance Directives
- Advance care planning
- Implement existing policy and guidance:
  - Living and Dying Well
  - Shaping Bereavement Care recommendations
  - Scottish Patient Safety Prog approach to caring for patients deteriorating in hospital
- Develop and implement palliative care clinical guidelines for generalists
- Share patient information across health & care services (electronic Key Information Summary – eKis)
- Use evidence and experience to improve approach to care in last days and hours of life
- Systems, processes and resources are available to allow staff the time and support needed to apply new practice of providing good end of life care

Reach
- Older people who are healthy, active and independent including carers
- Older people who are at risk/ in transition including carers
- Older people who are frail, who have a long term progressive condition, or who have high support needs, and their carers

Social Environment is more age-friendly
- Talking about and planning for decline, death and dying is perceived as normal and encouraged within families and communities
- Families and communities know how to help and support people in times of increased health need
- People get the support they need from formal services and from their family and community

More people ‘live well’ as their health declines
- People have fewer concerns about the practical and emotional aspects of decline, dying and death
- People are less anxious about dying and bereavement

More old people ‘die well’
- In a place of their choice
- With pain/ other symptoms controlled
- With their end of life care wishes respected

Medium term Outcomes
- More people aware of benefits of advance planning for decline, death and bereavement
- More people have access to information and practical planning and advice services
- More people use end of life planning and advice services and discuss and plan for their decline/death with family and friends in a constructive way
- More people ‘identified as approaching end of life and have Anticipatory Care Plans (ACP) including Key Information Summaries
- Increased recognition of cross-cutting social impacts of decline and death

RISKS AND ASSUMPTIONS

RISKS:
- More people identified as declining
- Care staff are more able to provide care in their homes
- People have access to advance care planning

ASSUMPTIONS:
- More people are better able to discuss and plan for their end of life
- Families and communities know how to help and support people
- People are less anxious about dying and bereavement
- People have fewer concerns about the practical and emotional aspects of decline, dying and death
- More old people ‘die well’ in a place of their choice
- With pain/ other symptoms controlled
- With their end of life care wishes respected