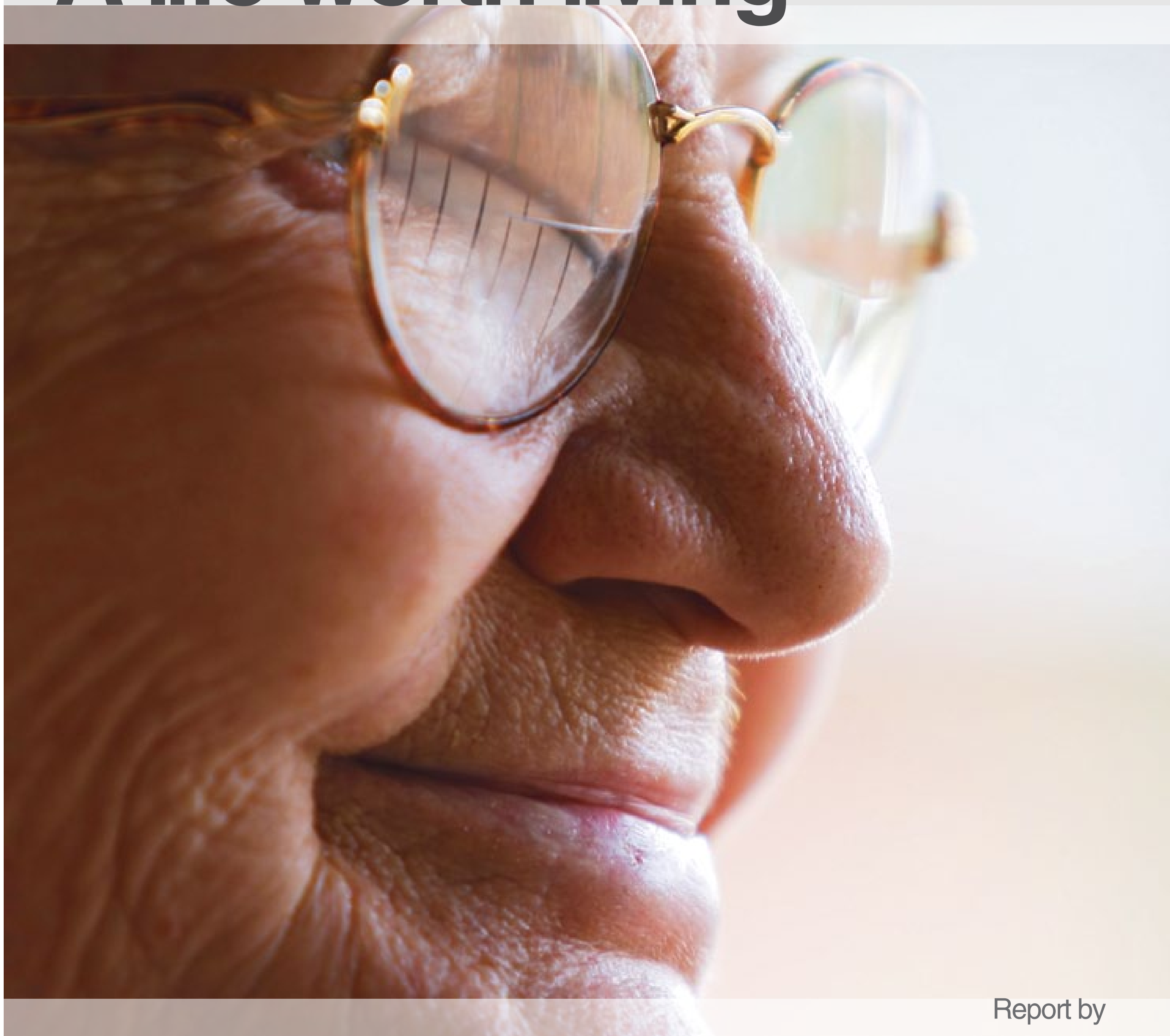
A life worth living



Report by

Alan Sinclair

October 2011

SCVO

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The views, errors, conclusions and recommendations in the report are of my own making.

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Chapter 1: Introduction

Background

A frog will sit comfortably at the bottom of a bucket of cold water or, if it decides to, leap out. If you very gradually bring the water temperature up, it will luxuriate in the comfort. Up to a point, this is very pleasant for the frog. However, bring the water to boiling point, and you end up with no leaping and a boiled frog.

When the NHS was established in 1948, it was designed to provide primary health care and acute services for all, regardless of income. We have grown to depend upon an all-embracing health service that will diagnose our symptoms; prescribe the medicine; carry out the procedures; care for us until we get better; and look after us until we die.

However, there has been a subtle, but significant, shift in the water temperature. People born between 1946 and 1964, the “baby boomers”, will live longer than previous generations. Thanks to birth control, they have fewer children. This means that there will be fewer young people to support an elderly population, which is living longer into older age with all the associated multiple health conditions and degenerative diseases such as dementia, cancer, osteoporosis and diabetes. Doubts about how we could meet the increased needs and costs of health and care preceded the financial crisis. More importantly **many were asking whether, even in easier financial times, we would want to continue spending in the same way. The answer is a loud “no”. This is because, as well as being unsustainable, the current system does not meet our needs for a more personal and sensitive system of care.**

It was in this context that the Carnegie UK Trust and the Scottish Council of Voluntary Organisations (SCVO) commissioned this work to address the challenge which ranges across policy and politics; health; formal and informal care; economics; morality; what the third sector does; as well as what individuals need and want for themselves, their families and communities; and their responsibilities (financial and otherwise) as family and community members.

The challenge

The nub of the challenge is this:

Spending on managing health conditions is unsustainable and so too is the demography of care. What was once a relatively clear line between care and health has become tangled. The third sector, in all its diversity, has a big part to play in supporting and improving individual and collective health. But we do not have a road map for getting there – yet.

A road map is of no use if you cannot locate that big green arrow you find on public maps that tells you where you are nor does it help if you do not know where you want to go.

Looking ahead

This report starts by taking stock of what it is that people want as they get older. It reviews the patterns, the emerging policy and the implications for the personal and state pocket of an ageing population. At its heart this report examines how our society, young and old, can pursue a good life. Today's middle aged people are likely to be attending to the needs of their elderly parents but with their own older years just coming into view it is others in their 20s and 30s and younger who will ultimately carry greater responsibility for older generations. Collectively, through our earnings and taxation, we all have to pick up some of the costs for the ageing population.

It is comforting, but probably unrealistic, to expect that the NHS or the government will do it all for us: whether it's providing good health and care or keeping the roads open when there is an enormous dump of snow. This gap between expectations and reality is most apparent in health and care of the elderly. Due to the "baby boomer bulge" the gap will become the gap will become even greater over the next four decades, with less public money to spend and more old people to care for.

A sense of direction

The current economic situation means that younger generation are already feeling the pain of youth unemployment and under-employment, the cut-back of further education funding, reduced starting salaries and difficulties in getting a first mortgage or affordable secure rented housing. These economic problems will become compounded when the reality of an aging population catches up with us. With due consideration to fairness, and the sums involved, we need a new picture and language to discuss how we can achieve a good standard of life for our aging population.

An agreement is needed on the direction we are to take — otherwise the map is redundant. We need a narrative that gives purpose to our actions and the direction we set.

Before going on to look at what good is already happening, usually in small but deliberate ways, we need a picture of the desired end position.

In summary, it is something like this: ageing is a normal part of life; it is not a clinical condition. As people age, they want to get on with life, be independent, connected, respected and live in their own homes. They value quality of life as much as, or even more than, quantity. At the end they want a pain-free and dignified death.

We need a more localised health system that helps to keep people healthy and supports them when it is needed in their own community, with the help of friends and family. Such a system would reduce the need for hospital stays and residential care. There are also issues about inter-generational justice and fairness. These result from the economics of the financial crisis, its aftermath and the fact that so many people at one time are dropping retiring and gradually incurring increased health and care costs which, in the current system, fall to the next generation of tax payers and public borrowing to fund.

Moving the blocks

Our desired picture has right on its side but also practicality. It can be realised if two big blocks move.

The state has to intervene and reorganise its affairs, encouraging collaboration between health and care to meet the needs of older people with multiple conditions. It also has to recalibrate the welfare state. Many baby boomers can afford to contribute to their own care, so there should be a levy or insurance system to gain their contributions. These would be limited, with the state picking up the shortfall as well as those of the many who plainly cannot afford to pay at all.

Another side to the picture is that we all need to do more to look after ourselves and others as we age. You call this self help, mutual help, getting on with life, friends and family or reinvigorating a sense of neighbourliness.

Many people already do this. But we need to foster the means and mechanisms to allow more people to give expression to their humanity and ability to care. The third sector has a major role in mobilising good will and binding it together at a local and national level in order to strike a new balance between the state and its people.

This is an issue which affects everyone. While the baby boomer generation is sandwiched between the young and the old, today's elderly people deserve better lives, and younger people need to know what lies ahead. This is arguably the most significant personal and public policy issue facing Scotland between now and 2050. Both the state and the third sector need to engage and author much of the necessary transition.

The report which follows explores these issues further, frames and reframes the challenges and discusses whether there is a new role for the third sector which utilizes its core values to make that transition. It concludes with recommendations for both the public and the third sectors.

If we change in time, we leap from the bucket. If we get too comfortable with what we have now, we will boil.

Chapter 2: What do people want as they get older?[1]

As they get older, people want to have control of their lives, be independent and stay in their own homes, be respected and treated fairly, have decent neighbours and do what they want to do with their friends and family. Life in older age is about having a sense of belonging and purpose, doing similar things to those we did when we were younger but with a different emphasis. Older people are not a homogenous group, there can be vast differences in capabilities and attitudes of a 60 something and a centenarian and, of course, all the other normal social, cultural and economic differences apply. Research indicates that going into hospital in older age for a prolonged spell is a slippery slope to the loss of independence. Moving into a care home is usually seen as a very last resort for those who are in very poor health and are a danger to themselves. We fear ill health and dread dementia and losing our reason. There are financial concerns: have we put enough, or any, money away? Will our pension (if we have one) hold up? What might we need to spend on care? And, what will our last days be like?

How people in general perceive old age is in marked contrast to the literature that surrounds ageing. Old people are typically seen as a bundle of symptoms, a burden, and a potentially destabilising threat to the health and care system.

Doctors are trained to look after us, make us better and send us back to get on with lives. In turn, we expect doctors to fix us and keep us alive. They are increasingly likely to be sued if they don't.

For those now in middle age (often women), looking after or supporting elderly relatives can be an impossible financial, emotional and practical strain. Families separated by long distances, with jobs to go to and especially those in the so-called "sandwich years" which still have young children to support find it hard to approach the task with a light heart.. Unless we are very careful, a gentle conspiracy between the medical profession and the public will lead to old age being seen as a clinical exercise in managing symptoms, conditions and budgets. If, however, we turn the prism around slightly, and become that elderly person, we can see that we would want to have purpose, dignity and meaningful relationships. Being old is part of life; it is natural, and a stage – not an illness suffered by a different species.

1 The views in this chapter are largely derived from Delivering public services: service users experiences of the third sector, National Consumer Council; surveys and group sessions to engage with public opinion commissioned by the Joint Improvement Team in Scotland and Life after work: what Scotland's baby boomers want as they grow older, Consumer Focus Scotland

Money and fairness

In many ways, the generation that is now moving into old age is very different from before. The differences between baby boomers are also important. While some have an occupational pension on top of the state pension and assets such as substantial property to cushion and support old age, others have very little. The Scottish omnibus survey of March 2011 questioned a representative sample of the Scottish population; here are the results on financial preparation for care needs:

Arrangements in place to take care of future care needs	%
I have/contribute to a pension scheme and have savings or assets which I expect to cover any care needs	30
I contribute to a pension scheme but find it difficult to make any further financial provision for my care needs in the future	36
I am unable to make any financial provision for my future care needs	14
I choose not to make any provision for my future care needs but expect the state to take of my needs	4
I haven't given much thought to the provision of the care and support I might need when I am older	11
Other	4
N	926

Money and fairness – a fault line

Having paid tax and National Insurance for decades, baby boomers, whether or not they have assets, strongly believe they are entitled to state funding for care in old age. If they do have a nest egg, they want to "keep it for a rainy day" or pass it onto their children, and not spend it on care in old age. Focus groups indicate that many people do not understand that the taxpayers of today pay for the health and care costs of the current elderly population.

In England, in July 2011, the Dilnot Commission published its report, "Fair Care Funding" which also found this lack of understanding. The commission has proposed that the UK Government reconciles individual wealth with state provision for care. A total cap on personal expenditure on care would be set at £35,000; once an individual has spent this amount, the state would meet the remaining costs. People without assets would receive care and those with assets would be means tested. Those with

assets of £100,000 or more would be expected to meet their care costs up to the cap.

A great benefit of this proposal is that it provides clarity and certainty for older people. There is a limit on what any single person can expect to pay and a scheme for sharing costs between people who can afford to pay and the state. The greatest unpredictable risk - a lengthy stay in complex care or a nursing home - rests with the state.

At the time of writing, it is not known if the Westminster government will accept the proposal.

But, given the sheer numbers and longevity of the baby boomer generation, it is hard to see how something will not give, either in reduced quality of care or in requiring people to release wealth which is tied up in houses.

Care

People want to make the most of, and enjoy, their retirement for as long as possible but they also recognise that, one day, they are likely to need caring support. They want to stay in their own homes; shape (co-produce and self-direct) and choose the type of care they will receive, who provides it and how. They also want services (professional and semi-professional) to work better together and more support for carers and people suffering from dementia. If, as a last resort, they need to move into a care home, they want it to be small, and to provide personal and respectful care.

The priorities of commissioners and users of services differ. Commissioners are more concerned about when and what specific services are provided. Service users are more concerned about the nature and quality of services. For example, do staff have the time or inclination (or permission) to offer companionship, human warmth or do anything else that is not on the prescribed list of duties?

A good death

In the north east of England, a large-scale consultative exercise involving the public and professionals studied compassion at end of life and what makes “a good death”. The conclusions may be equally valid in Scotland.

They include:

- All of us should have the right, at the end of life, to experience a good death and our family, partners or other carers deserve support and compassion at this time.

- Sensitive and appropriate end of life support should begin at the time illness is identified and continue throughout ill health, during death and in bereavement. It should be available to people coming to the end of life at any age and from any condition (at the moment palliative care is more readily available to cancer patients).

- This charter for the north east will guide health, social care, community, voluntary and other organisations, groups or individuals who plan, develop and provide end of life care or support. It will help to ensure the right services are available at the right time for individuals who are dying, their families and carers. All care providers should be aware of the charter, and its impact on their work, not only those who work specifically in end of life services.

- To see death acknowledged as a part of life.

A 2009 poll, commissioned by Dying Matters, explored the extent to which people aged 18 onwards had discussed dying. 70% had not discussed it; with the most common reason given that death was a long way off. As people get older, they begin to value quality of life above longevity. This is important because, as outlined in subsequent chapters, medical practice is largely based on length rather than quality of life.

In the Scottish “Reshaping care for older people - omnibus survey”, one significant area where people wanted to exercise choice was in the choice to die and some people advocated that assisted suicide and euthanasia should be legalised.

People need to be able to talk comfortably and constructively about death and dying, with children and families seeing death as part of life. This is the view of the Scottish Partnership for Palliative Care which acts as a voice for people approaching death. People also want to be able to make choices relevant to their own death. Professionals and communities of all kinds would benefit from support in dealing with dying, bereavement and loss.

What do people want and what is possible?

Looking at what baby boomers want in old age is a good starting, or reference, point for shaping what health and care should look like over the next 30 to 40 years. But this needs to be matched with what is realistic. A series of tensions across health and care emerges from the work of Finland's Professor Kroger who has examined international practice on these issues:

- Central v local government
- Primary v secondary health
- Acute health v prevention
- Top down v bottom up
- Inequalities of health v longevity
- Local authorities v health boards
- Social v health care
- Home v residential care
- Municipal v voluntary v private care
- Care workers v care users
- All care workers v informal carers and family
- Hard evidence v soft outcomes

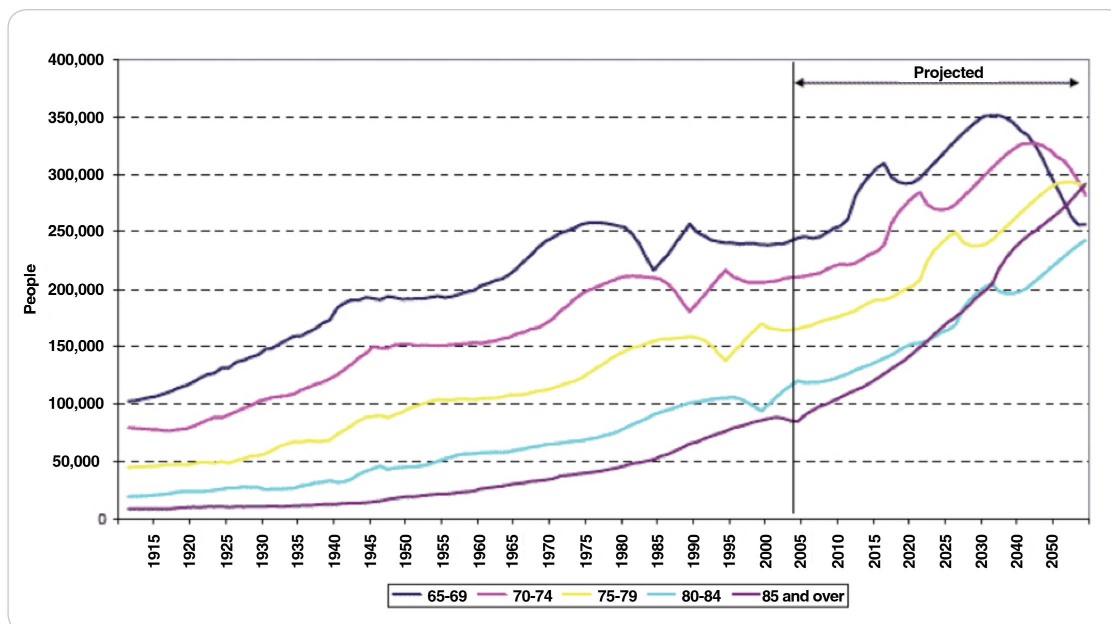
Old age belongs to all of us. It is about life, not a clinical condition that needs care. We need to find and create the conditions that make life worth living for people though the different stages of older age and a dignified death when it comes. The challenge for all of us - institutions, government, NHS, local authorities, the voluntary sector, individuals and communities - is to take the issue head on.

But, firstly, we need a clear definition and picture of the challenge.

Chapter 3: Context

Baby boomers were born between 1946 and 1964. This post-war increase in the birth rate has been made more challenging by social changes which have led the baby boomers to have fewer children per family than previous generations. Thanks to medical science and greater prosperity more will live into old age and very old age (although many will have multiple, long-term health conditions) than earlier generations. . There are several dimensions to this picture, and there are unexpected consequences, some of which we are only dimly aware of or are only known to a few.
Population and longevity

Actual and projected population in Scotland

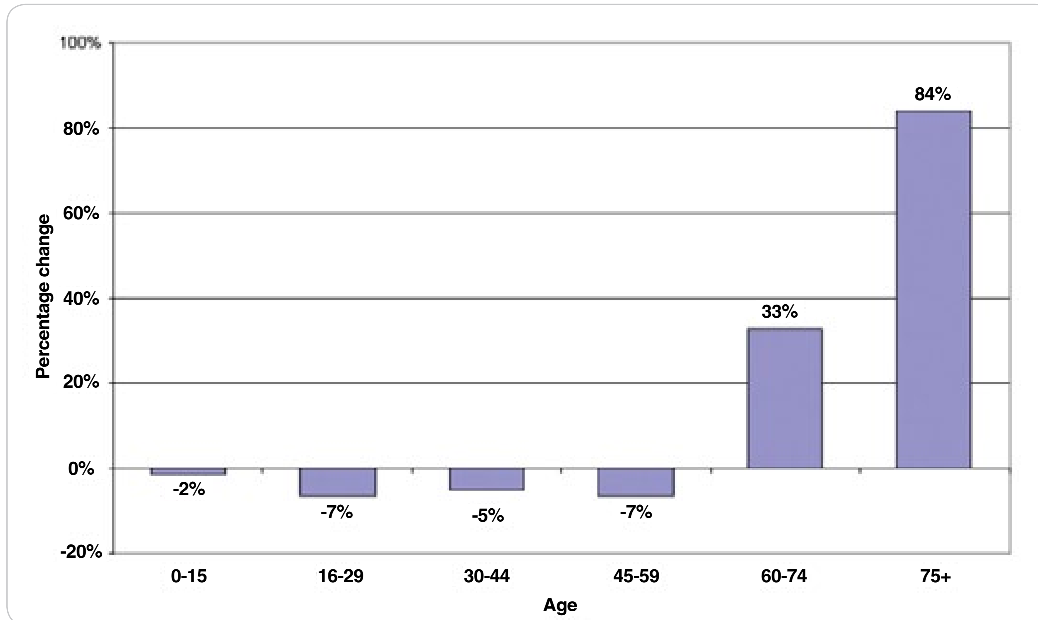


Source: Registrar General for Scotland 2005

The general trend is clear: more and more people are getting old. Scotland's population of 65 years plus will rise by 62% by 2031. Scotland's population of 85 years plus will increase by 144% by 2031.

What is extraordinarily significant is the number of people living beyond 85 years of age. If current conditions prevail, there will be a six-fold increase in the number of people living beyond 85 years between 1990 and 2040.

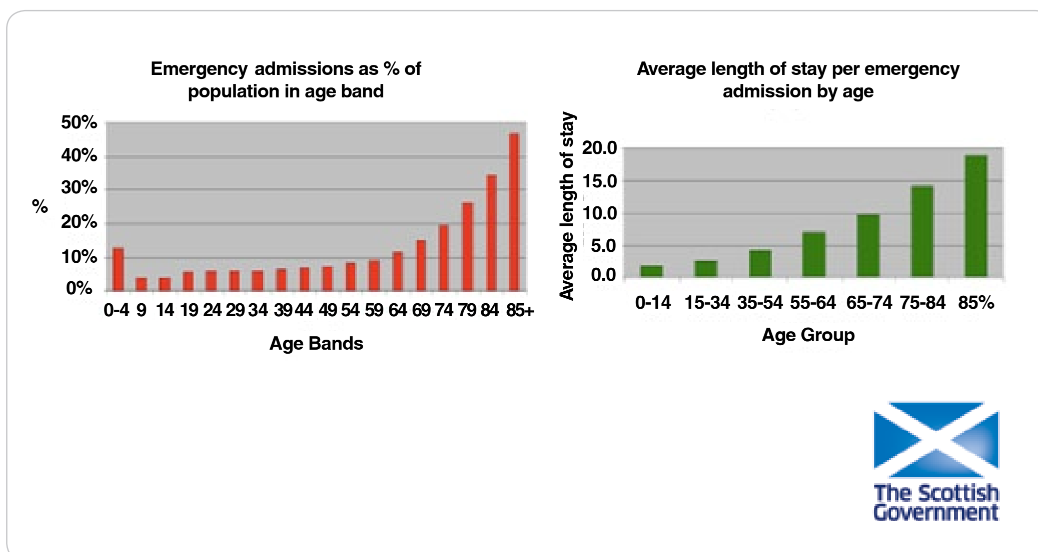
Projected percentage change of age group, 2008-2033



Source: Registrar General for Scotland, 2009

Longevity can be a blessing or it can be a curse. There is no getting away from the fact that, in different ways, as we age, we wear out and experience more minor and acute conditions. This is a personal experience but it has a wider impact on public services and expenditure.

Emergency Admissions to hospital 2007-08: Age Profile



£4.5bn was spent in total on health and social care for people aged over 65. That works out at £5,500 per person on average. Nearly two thirds of this spend was in hospital or in care homes.

Emergency admissions to hospital alone accounted for one third of the total spend — about £1.4bn. Too often, emergency admission is a result of poor prior care and the absence of a better alternative in the community. Emergency admission is also hugely disorientating for an elderly person and often results in a poor outcome.

These two charts show emergency admissions to hospital according to age, and the average length of stay per emergency admission by age. There are major variations across health board areas and GP practices. Interestingly, evidence shows that, the nearer an individual lives to a hospital the more likely they are to be admitted. The older an individual is, the more likely they are to be admitted as an emergency, and the longer they are likely to stay. And, all too frequently, the next port of call is the long-term care home.

Assuming the current model of service, the Scottish Government's own report *"Shifting the Balance of Care"* estimates an annual increase in investment in health and social care services for older people "of £1.1 billion by 2016 and £3.5 billion by 2031, a real increase of 24% and 74% respectively over 2007/8 levels".

If current trends continue, we could fill a new district general hospital every couple of years and we will be building nursing homes at the rate the Chinese build power stations. And this at a time when public expenditure is falling. Although the Scottish Government has ring-fenced health expenditure there will be a reduction of 4 to 5% a year. Health costs, historically, have usually exceeded inflation. For example, in 2010-11, drug costs alone rose by 10%. Local authorities, with responsibility for care, are even based on conservative estimates, facing an annual 3% reduction in income.

The demands of health and care for an ageing population and the knock-on effect on budgets are already immense. There is a growing consensus that the current model of health and care is not affordable or sustainable.

This should fill us with concern but not with total dread. Much of the current model of health and care provision is, increasingly, at odds with what people want, as they get old. And the processes inherent in the health and care model are both undesirable and very costly. Most notably, unplanned admissions to hospital could be reduced through better support for elderly

people in the community. Many unplanned admissions of elderly people are the consequence of doctors not knowing what else to do and a lack of alternatives.

Once in hospital, an older person's coping mechanisms tend to deteriorate fast; there is growing concern about the tendency for elderly in-patients to experience delirium and disorientation. Often whatever medical condition caused the initial admission is swiftly followed by a growing sense of helplessness. Hospitals are, overwhelmingly, the biggest recruiting grounds for care homes. How then to get someone in this condition out of hospital? Hospitals want the person to move on and the local authority has to bear the costs from its social work budget. This phenomenon of "bed blocking" is the most public face of what is, in general, a dysfunctional relationship between managing the health and managing the care systems. Audit Scotland commented on this in its 2011 audit of the Community Health Partnerships.

Here are, I stress, rule of thumb costs per week for different options in Scotland. Some of these cost differentials reflect genuine differences in the severity of the illness or disability. If one person or thousands of people are in an inappropriate part of the hierarchy of care, it is not long before very substantial sums of expenditure are clocked up. These could be better spent in other ways.

Weekly cost:

Complex home care/palliative care.. **£900**

Nursing home care.. **£600**

Generalist care including rehab.. **£4,200**

Disease specific consultant care.. **£10,500**

Most people, when consulted, think that residential care and hospital are to be avoided. Clinically, economically and personally they are right. We can make major savings by reducing unplanned admissions to hospital and helping people, if they have to go into hospital, to get the support they need to go back to their homes as soon as is possible.

Another glaring peculiarity is the amount spent on the last few months or years of life. It is hard to find a precise figure, but it is safe to say that around 25% of an individual's lifetime health expenditure is in this period. Doctors are trained to keep people alive for as long as possible.

Given public spending and the demography of ageing, the issue is commonly framed as follows:

First framing of the challenge

People are living longer and current spending on managing health conditions and care is unsustainable. It looked difficult before the banking crisis but now it is grim. We need greater efficiency in health and care spend and to shift the balance to care in the community.

Current policy and practice — the gap

Briefly, I will offer a short overview of policy in Scotland on ageing, health and care – and the all too often neglected, dying with dignity.

Two observations need to be made. First, to date, the policy work has been the preserve of health politicians, civil servants and advisors. But who else should be round the table: transport, community, labour market and skills? How can we put older people and their needs at the centre of the debate and the services? Not older people as a set of symptoms, but older people who simply want to get on with life. If older people are to have a voice, there needs to be investment in advocacy for older people in order to make space at the table. This is especially true for the frailer and older old people. If not, older people will be treated by the medical industry like the proverbial joiner who only has a hammer and thus treats all problems as though they need a nail.

Second, in the instances when policy positions are clear and sensible on paper, we must be able to translate these into practice. In short, there is an implementation deficit syndrome and a lack of urgency. To turn the oil tanker around will take years, just as in the 1980s when Care in the Community was introduced as an alternative to institutionalised care.

In *“Building a Health Service Fit for the Future”*, published in 2005, a 20-year plan was set to shift the emphasis from hospital-based care to preventative and anticipatory management and care in the community. It recognised the need to manage the long-term conditions of the most vulnerable and integrate primary and secondary health care with social services. It pointed to the need to encourage people to take control over their own health and avoid unnecessary admissions to hospital by putting a greater emphasis on GPs, community health practices and community pharmacies.

"Better Health, Better Care" followed in 2007, highlighting health improvement, tackling health inequalities and improving the quality of health care. An action plan extended the anticipatory care approach and there was an emphasis on ensuring that older people get the services and support they need to live independently at home, with carers, or in a care home.

In 2008, the Scottish Government published *"Living and Dying Well, a national action plan for palliative and end of life care"*. It aimed to extend the reach of palliative care beyond cancer patients nearing death. It set out a process for assessing the needs of the person dying and their carers; meeting those needs; and communicating the plan across different settings and disciplines. It recognised that death needed to be more grounded in what we talk about and how we organise ourselves.

In 2004, the Joint Improvement Team was established to work with local health and care partnerships across Scotland. In 2008, the Scottish Government published the admirable, *"Shifting the Balance of Care"* report which dug into the issues and asked people what they wanted from old age and care services. Elements of this report have been drawn from its work. The report highlighted eight areas for improvement:

- maximise flexible and responsive care at home with support for carers
- integrate health and social care for people in need and at risk
- reduce avoidable unscheduled attendances and admissions to hospital
- improve capacity and flow management for scheduled care
- extend the range of services outside acute hospitals provided by non-medical practitioners
- improve access to care for remote and rural populations
- improve palliative and end-of-life care
- improve joint use of resources (revenue and capital)

The Joint Improvement Team was established to work with local health and care partnerships. It is supporting a £70m Change Fund across all of Scotland's health, housing and social care partnerships (including the third sector) with a view to doing what it says on the tin: shifting the balance of care to the community. It is too early to know the impact of the fund — will

it lead to a more preventative approach or, in the midst of budget cuts, be absorbed in plugging gaps?

With this raft of policy, why is the gap so big between policy and shifting practice? Why do we suffer from implementation deficit syndrome?

Perhaps it is fear of getting it wrong or a disproportionate focus on other targets? If you were a health board chair or chief executive, what issues would you get a public lashing for or get your collar felt by the Minister? Waiting times, other nationally-set health targets and MRSA top the list. Health and care for older people have not, as yet, scandals apart, made it to anywhere near the top of the list of issues (such as hospital closures) which cause a furore. When Newsnight interviews the First Minister about health and care of the elderly and the Daily Record and Sun comment thoughtfully about the dilemmas we face in ageing, a flag should be run up the nearest flag pole.

Our health and care infrastructure of GP services through to large general hospitals has perpetuated the intensive hospital and care system. Intensive, hospital-centric health care has grown with the support of hospitals, the public and politicians. And the Change Fund, though welcome, is a very small tool for a very big job. Its £70m annual expenditure is dwarfed by the annual cost of, for example, £1.4bn for unplanned admissions.

What gets measured, gets managed, a popular slogan and very true for much of business and the public sector. Health Boards' key targets and measures, the so-called HEAT targets, pay little attention to the need to turn the tanker.

Change

Change comes about in two ways – through planning or crisis.

Programme management or planned change involves many factors including: assessing the current situation, seeing what is coming down the track, thinking about what ought to be done, measuring the scope of the exercise, deciding who needs to be involved at each stage, making a major commitment, winning buy-in from different players, creating a programme management process, carefully managing that process and communicating and reinforcing the need for change with all players over time. A programme management process is a logical and well-tried method used in major transformations in the public and private sectors. More piecemeal variations are also possible.

Crisis is the other way of bringing about change. Think Libya or the banking crisis: the status quo is not sustainable, breaking point has been hit and miscellaneous forces are galvanised at breakneck speed to sort something out.

Change does not come about by government publishing an edict or a strategy document or exhorting folk to get their act together. Even legislative change is of limited value unless there is buy-in and serious management of the process.

So, will we stick with the status quo on health and care and, over time, fall into a crisis or will we actively manage a change process? At the moment, change by crisis seems the most likely way to jolt us out of our lethargy. But, if we don't jump in time, like the frog, we will boil.

Chapter 4: The crisis of fewer hands

People pay taxes. Workers and employers pay National Insurance, a name that suggests that what we have given to the state will, like an insurance policy, come to our aid later. The reality is somewhat different. Government finance is one large current account with a borrowing facility. Tax and NI revenues, mostly from people in work, plus borrowing, pay for the young who do not work and for the pension and benefits which are so vital to the well-being of most retired people.. It is all part of the social contract which underpins the welfare state.

Currently, there are three people in work to support one older person. By around 2035, there will only be two people in work to support each older person.

Take that over an entire population and the implication is significant. There is more. A multiple whammy is coming, glacier-like fashion, in our direction. Fewer people will produce and earn, more will claim state pensions, and a bigger group will need health care and, as they age, more paid care.

That is the general picture. But we need more precision.

Fiscal implications of ageing

The fiscal implications of ageing are clear as we know how many young, middle aged and old people there are and have a good idea of their health and care needs and life expectancy.

In its paper, *"The Fiscal Implications of the Global Economic and Financial Crisis"* the International Monetary Fund (IMF) states: "In spite of the large financial costs of the (financial) crisis, the major threat to long-term fiscal solvency is still represented, at least in the advanced countries, by unfavourable demographic trends."

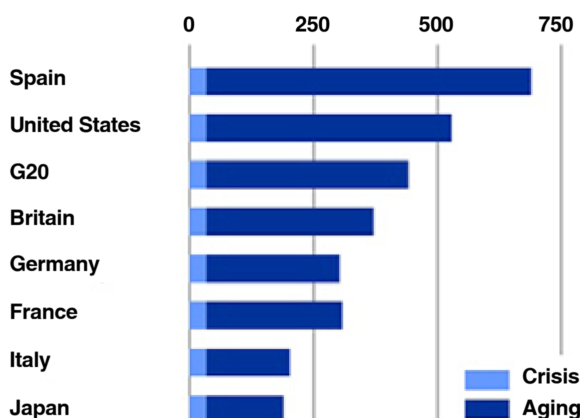
What the IMF is saying is that over the next 40 years, until 2050 when the baby boomer effect plays itself out, the costs of the banking bailout, fiscal stimulus and automatic stabilisers (increased unemployment payments and the like) are dwarfed by the effects of ageing.

The chart below, compiled by The Economist from IMF data, shows that for developed industrialised countries, the fiscal burden up to 2050 will be made up of 10% from the fiscal crisis and 90% from ageing. Without getting bogged down, NPV means "net present value", a measure of

present worth. It is a central tool, used in long-term planning by economists and accountants, to measure the excess or shortfall of cash flows, in present value terms, once financing charges are met.

What crisis?

Net present value of impact on fiscal deficit of recent crisis and age-related spending to 2050
% of GDP



Source: IMF

An unpleasant medicine is prescribed by the IMF – reform the entitlement to pensions, health and care. For "reform" read "reduce".

If the IMF is right, it is a scary scenario. If the IMF is only partially accurate, it reframes the challenge and debate about health, care and demographics. In the first framing of the issue, the challenge of ageing and care for baby boomers was judged more difficult because of the financial crisis. In this formulation, with fewer hands, two people and not three supporting each older person, the actual size of the public pot and borrowing capacity is under threat. In the UK's case, the fiscal challenge of fewer hands is nine times greater than the financial collapse.

In July 2011, the Office of Budget Responsibility (OBR) published the *"Fiscal Sustainability Report"* – an examination of spending and revenues over the next 50 years in the UK. Working with the best assumptions and information about the trends available and how they interact, it estimated that the increase in health care, state pension and long-term care would raise public spending by 5.3% of national income, an equivalent figure to our total current spend on defence or primary school education. In launching the report, Robert Chote, the chairman of the OBR, described the outlook as "unsustainable". Even working with a conservative projection on the rise of health costs, Chote concludes, "Once the fiscal consolidation we are embarked upon is out of the way, we will probably need some more tax increases or public spending cuts to stop public sector debt rising indefinitely in the longer term."

Our social contract is in danger of being eroded and broken. More and more resource going into very marginal gains in life expectancy makes it

more and more difficult to support babies and the young, the very people who need the right start in life — for themselves but also so that they can work, pay their taxes and be full members of society.

There are serious numbers at stake with major implications. Working beyond the normal retirement age by a few years would improve the picture: extra taxes would be raised and it would lessen the strain on pensions. If more effective ways can be found to deliver or minimise what are currently health costs and we can find new models for providing care that are not as costly, the picture becomes more manageable.

The Scottish Government economic service is concerned with monitoring the Westminster budget and, through the Barnet Formula, making sure that Scotland gets its fair share. Within Scotland, it provides a budget management and forecasting service.

What it does not do is model or run scenarios on what is likely to happen to UK public income and expenditure. UK and Scotland long-trend growth rates are being affected by the financial crisis and the recession that follows in its wake. Default in Greece, Ireland and Portugal seems ever more likely with further economic dislocation and stagnation.

In Scotland, we have a big problem. The work has still to be done by governments to get a handle on the scale and likely range. An appropriate collective response will be different in scale and urgency if the problem is big, huge or enormous. Enormous is where I would put my money.

Robust political economy

We live in a very robust political economy that has fought world wars and transformed an economy once dominated by the coal and steel industries. While facing the demographic challenge of the next 40 years, we will also navigate peak oil, climate change and the beneficial but destabilising effects of trade and globalisation. At a personal level, UK wages, the Office for National Statistics tells us, have not risen in real terms since 2005 – the longest sustained freeze in living standards since the 1920s. If you are in work at the start of 2013, and have children and a mortgage, there is a strong likelihood that, given tax and national insurance rises, inflation, an increase in mortgage rates and the ending of child benefit your spending power will be down by 15-20%.

Scotland needs a commission to provide an objective assessment of the fiscal implications of ageing.

cont.

My sense or feel for the numbers is this. Even if we are able to improve our health and care delivery model and find ways of choking off demand for hospital beds and reducing the demand for nursing home beds, (both of which we need to pursue with rigour), there will still be an enormous gap between our demand for health and care services and what, in a strained financial climate, we can afford.

So, we need to define, even more carefully, the challenge we face:

Second framing of the challenge

People are living longer – the status quo for health and care is not sustainable. The combined effects of the financial crisis and the fact that two people in work will need to support one retired person means that we need to seriously rework our approach to health and care.

This new framing, which suggests an even more difficult and complex challenge, requires us to look at different types of solutions. There are no magic bullets or simple answers.

Chapter 5: Good practice in health and care

Generals, famously, fight their battles using the strategy of the previous war. In solving the challenge, we need to move from where we are headed to where we ought to go. Our mindset is affluence; our reality is austerity. This takes us into a new battle-ground: what we have been doing for the last 40 years will not work over the next 40.That means new strategies and tactics and a new mindset.

There are four critical questions. Finding answers to these will take us a step closer to solving what is arguably the greatest domestic, personal and public policy challenge of the next 40 years:

1. **What health and social care will the government, the NHS and local authorities deliver?**

2. **What more will people do for themselves?**

3. **What will communities and voluntary organisations deliver?**

4. **How can the government and voluntary organisations help in reshaping expectations and supporting transformation?**

What can the government, NHS and local authorities do?

There are already examples of where we need to get to in the future. They may be embryonic or at the scale of a town rather than the whole country but they, nevertheless, offer a glimpse of what is possible. But first, the Scottish Government needs to establish where health and care for elderly people sit in its hierarchy of objectives.

Striking the balance

Meeting the needs of an ageing population cannot be achieved at the expense of other pressing needs. There continue to be major health inequalities. Improving the early years of life, reducing violence and the incidence of mental health problems, drinking less alcohol and exercising more would radically improve our health right across the adult population. This is a collective responsibility.

In countries like Holland, prevention and early intervention are at the heart of the system. The rest of this chapter describes examples of services which serve the needs of older people better.

Functional autonomy tool – Quebec

Professor John Frank, a Canadian who heads the Scottish Collaboration for Public Health and Policy in Edinburgh, drew my attention to the fact that Quebec has been faster out of the blocks in responding to an ageing population concluding that a hospital-centric model is inappropriate for "socio-health". In the new model, first-line health service and home care form the crux of the system.

In 1999, policy people, managers and care and clinical practitioners worked collaboratively to find and develop mechanisms and tools to enable integrated service delivery. Note the aim was not, as we have fruitlessly pursued in Scotland, to effect structural change. Out of this process and collaboration, a functional autonomy tool has been developed to adopt a different conceptual approach based on client or patient autonomy as opposed to the need for nursing services. To make this work practically, they had to develop tools to monitor organisations and how they managed their operations and finance. The profiles reconcile clinical evaluation with case management information.

In Quebec, the "autonomy profiles ushered a shift away from nursing-care indicators towards an approach based on autonomy profiles"[2]. As well as the gain in empowering clients, it has affected the bigger picture by collecting information and quantifying the urgent need to invest in homecare.

Health and care – Nairn

I want to grow old and die in Nairn. Not literally in Nairn, but in a Nairn lifted to the central belt where my roots are and where my family and friends live. I do not have perfect knowledge, but when I walked round and talked to the people in the Nairn Town and County Hospital, I had a strong feeling that this was a humanly decent place where a very good technical health service is provided. Being that way inclined, I have also looked at their management information statistics and their performance looks very good.

Over several years, the GPs in Nairn, with Dr Alastair Noble in the vanguard and now Dr Adrian Baker as the Executive Practice Lead, have

2 Rejean Hébert, 2005,"Integrated service delivery to ensure persons' functional autonomy"

created an ethos and a facility that positions itself between Raigmore, the big district general hospital in Inverness, and people who cannot be looked after in their own homes and their own beds. In their 19 in-patient beds, they also help people who have been discharged from Raigmore and require medical support before going home; provide Accident and Emergency services; physiotherapy, X-ray and ultrasound facilities; minor surgery; and palliative care. And none of your NHS 24 here: they also provide an out-of-hours primary care service.

The town's GPs; nurses; physiotherapists; occupational therapists; speech and language therapists; and social work care assessors and managers are all located under the one roof. Formal and informal case management across the different disciplines help patients get the best service.

The ethos is to try to prevent the flow of people into its hospital facility by treating them in the surgery or in their homes and, if they do go to the big hospital, to help them get back to Nairn and their own homes as quickly as possible. On the day I visited, two community nurses were busy making up and dispatching telemonitoring packs to selected people who had suffered a stroke or developed a heart problem.

The packs contained instruments for taking blood pressure, heart rate, and ECG and a modem for transmitting the results. It is early days in telehealth care but trials elsewhere have shown that survival increases, visits to hospital are reduced and patients feel safer. It is an approach that improves monitoring but also positively influences patients' use of medicines, diet and lifestyle.

Among the outpatient clinics are dementia care, stroke services, NHS dentists, alcohol detox and self-help workers for depression, and district nurses. Visiting times are fixed but flexibility is offered.

In supporting older people and the aged, the practice works round five practical choices:

- self care-telecare and voluntary sector support
- enhanced home care – statutory and voluntary sector; Crossroads, Marie Curie and befrienders
- care home bed
- community hospital bed
- consultant bed in Raigmore

They have analysed patient lists to identify the 500 people most at risk of hospital admission. Through talking to each patient, they produced an “advanced directive” to guide the ambulance driver and doctor when a critical moment is reached and the person is not able to make a reasonable judgement about their treatment. This also gives details about the legal or in-a-crisis steps to be taken on care or support and the degree of aggressiveness of treatment and resuscitation. A central record is held of the advanced directive and a copy is kept in a prominent place in the patient’s home.

Nairn shows that the link between health and care does not require wholesale restructuring. Care and health have been fused together by proximity, mindset, design of service and familiarity.

Economically, does it add up? For total mapped spend per locality per weighted head of the population over 65 years of age, the average cost across the Highlands is £3,400 per head against the cost for Nairn of £2,900 - a gain of 15% to the health budget for a better service. While recognising that Nairn is not the east end of Glasgow, it provides evidence that it is possible to deliver a better service at less cost.

Minister – what should I do?

In early 2010, the Junior Health Minister, Shona Robison, had finished addressing an audience in Dunblane about health and care, when the embarrassing spell that comes once questions are invited from the floor, was broken by an 80 year-old from Inverclyde. “Minister, I was in hospital and got first-rate treatment and was well looked after. When I came home I needed a carer. They were really helpful. I could not have managed on my own. After another a few weeks, I knew I could do more for myself. I had trouble getting my messages and asked the carer if she could come less and use the extra time to do some shopping for me. She told me that she was not paid to go for messages and it would be daft to cut back on the hours in the care package as it might all be taken away. Minister, what do you suggest I do?”

Partners, families, neighbours and friends provide a great deal of care informally. Formal care is commissioned and when you commission a service you do it against, what is in effect, a checklist of services and you struggle to turn on a tap that provides sensitivity and love. Large-scale commissioning spawns an industrial approach. It provides a technical service to a set standard and timetable. Care is more elusive.

Good care is indeterminate in nature and lasts for an indeterminate amount of time. It is about love, listening to people, being sensitive, being available

and reassuring and meeting real needs. A checklist of care allocates time for bathing, sorting medicines, preparing food for the client and washing up and getting them into or out of bed before hotfooting it to the next client. It is hard for dedicated staff when they are caught up in what feels like an industrial process.

A new way of organising ourselves is needed; a new paradigm for people to age taking into account all their different personalities and circumstances and, simultaneously, to manage long-term conditions: heart problems, strokes, cancers, depression, diabetes, dementia, obesity and mobility problems – the list goes on. In this new paradigm, care and sensitivity become as important, or more important, than technical fixes.

The following approaches shine a light on the future.

Rosemary and her mother – North Lanarkshire

Here is a story from North Lanarkshire, where the local authority has started to use personal budgets and self-directed care. In this example, financial support is given to a very elderly woman's carer, her daughter, Rosemary.

"The payments from the In Control programme have completely transformed not only my life but also my mother's life. I am 60 and a full-time carer for my mother who will be 90 later this year. We were really struggling financially. Over 10 years ago, I had to take early retirement on the grounds of ill health and my pension was reduced considerably. The Carer's Allowance – as all carers will know – is a sick joke. Since I have no brothers or sisters, and no relatives who are willing to help with the care of my mother, the entire job of looking after her falls to me. She is a really lively person but the strain of caring for her 24-hours a day was beginning to get to me. I used quite a lot of my pension money to buy in help from other people. Luckily, when I had practically reached the end of my tether, North Lanarkshire included me on its In Control pilot scheme. Now we have money to pay for care for my mother – in her own home — so that I can have a break for 12 hours a week. However, the best part is that we can now do what my mother loves best in the whole world – travelling."

Care takes on a new shape

Rosemary and her mother's improved well-being are down to the approach being pursued by the council and the NHS in North Lanarkshire which aims to provide personalised care, integrated day care and "re-ablement" (for people who might have lost their independence).

Duncan McKay and Joe McElhone are responsible within social work for community care services and older people. They know that a local authority department can never satisfactorily commission to meet the complex and changing care needs of different people and the family and friends who support them. Instead of commissioning, they take a different approach.

An assessment is made of the type and scale of need for each person. Once an assessment has been made, an indication or budget is set for the individual and their carers. In order to manage budgets, the final allocation to an individual is calculated in the context of the central budget limits. Once the person gets their allocation, it is then over to them to buy what best fits them – what they buy and whom they use is up to them – as long as it is legal. Originally, this was tested in North Lanarkshire and other parts of Scotland for people with learning difficulties and younger people who required care in the community, and it was found to work.

The philosophy is clear: stop running old folks homes and bussing people to day centres. They recognise that people want to be supported in their own homes and communities, so they are using what were residential homes as intermediate destinations or integrated day hospitals for older people coming out of hospital who need medical attention or physiotherapy before returning to their homes. They use the remaining homes and the resource freed to spend on people with more intensive needs. Pro rata to the population size, people are twice as likely to go into a care home in Glasgow City as in North Lanarkshire. Of course, closing homes and day centres can only work when there are alternatives. And that is exactly what they have been working on in North Lanarkshire in recent years.

Transforming older people's services – Scottish Borders Council

Motivated by an above average share of Scotland's elderly people, Scottish Borders Council initiated a major consultation, "Transforming Older People's Services". Following this, the council concluded that, "continuing with the current service model is not only financially unsustainable, but also undesirable".

It identified four work streams: prevention, early intervention, supporting older people in their homes and creating local and community capacity. Service users and trade unions were integral to the work.

In practice, this has meant providing existing services differently and re-designing council care home services. Day activities are now viewed as preventative services which enable older people to improve their general health and well-being.

A direction has been set. Older people want to stay in their own homes, so design support that enables them to do this. And if they have to go into hospital, then design services that will help them get back to independent living. The way of working is being transformed so that older people can maintain the independence they want and have greater self-determination in their choice of care.

The Scottish Borders has a sense of direction but it is very much a work in progress. I like to study what people have on their office walls and desks. In the room of the senior social worker responsible for older people's services in the Borders, was a little note stuck on the end of a whiteboard - "Are my decisions making people more or less dependent?"

Inspirational care in the Netherlands

A form of personalised budgets has led to a happy revolution in the Netherlands. Buurtzorg, (meaning community care), was started by a community nurse, Jos de Blok, who had become disillusioned as he moved from nursing into management roles. Why were managers earning so much more money than nurses and nurses taking all the frontline stress? Bigger and bigger organisations had been formed to deliver nursing and the shift was to provide checklist activities rather than solutions. Nursing had adopted "Taylorism" (moving from a craft and personal service to industrialisation and large-scale production) and he had had enough.

In 2006, he started his first Buurtzorg nursing team. It received payments from the insurance company and the AWBZ (government care fund). A Buurtzorg team has between four and 12 community nurses - they only employ community nurses. Community nurses are highly qualified.

Jos believes that it is impossible to do the job properly if care is focused on activities. Focusing on activities only makes the old people dependent. "The attitude, 'I have come to take care of you,'" says Jos, "is the wrong mindset and is reinforced by the market incentive of payment by hours attended."

Instead of following a checklist, the Buurtzorg nurse goes back to the fundamentals of community nursing:

- get to know each person's history
- understand their coping strategy
- meet the family and see how they feel

- talk to the doctor and others who supply a service
- ask what can the nurse do, what can the family do and what the person can do
- work out a way to withdraw or reduce hours of contact

It is a bottom-up approach building on what people can do and on trusting nursing professionals. Organically, the Buurtzorg teams have grown so that, today, over 3,000 community nurses in over 300 teams work across the country. Each team is responsible for making its own decisions; managing its own income and expenditure; setting its own work rota; proving 24-hour, seven days a week on call numbers; and linking up with doctors. About half the community nurses in the Netherlands have now moved over to Buurtzorg and the approach is still growing.

An IT system, with each nurse having a laptop, underpins all these autonomous teams, allowing them to manage client records; fill in their time sheets and expenses forms; plan their work load; post questions or look up regulations. Jos and the Buurtzorg's approach of encouraging each team to look after its own affairs and decisions and a bespoke IT system mean that overhead costs are kept to a minimum (7%). With over 3,200 frontline nurses, there are only 30 back up staff including Jos, IT, finance, personnel and coaches. National care inspection systems have given their work the highest quality rating in the country. GPs are happy because they know who to talk to and are reassured. Fund holders and managers are happy because Buurtzorg nurses claim fewer hours of support. The nurses are happy because they are doing the job that they came into nursing to do and managing their own affairs.

Do the people who receive the care benefit? I met Jos once and a coach twice. I did not meet any clients; but they assure me that they do. It is hard to imagine, given the basic approach and the rate at which nurses and doctors and clients have switched to Buurtzorg, that this is anything other than a mass migration of clients voting with their feet.

Can we in Scotland trust community nurses to work like this or do we always want to tie them to systems, checklists and controls? In Nairn, the GPs are empowered; in Holland, it is the community nurses. There must be a lesson here.

A good death

Personally, I would rather not think about it. It only happens to other people anyway. It will not happen to me. Old people die and I am not old.

What does it mean to have a "good death" and can we have permission to talk about it?

As medical science has improved, we are dealing with conditions that would have killed previous generations. As we get older and older, these conditions multiply to the extent that life has little quality. A conversation with a consultant who provides dialysis treatment summed it up, "We provide the treatment we technically can – not necessarily what is best for the patient." A GP said, "As cases become more specialised, each specialist makes their decisions according to an algorithm – the decisions that are made do not follow best general medical practice."

I remember my own grandmother, not known for her sense of humour, remarking shortly before her death at 92: "The only part of me that doesn't hurt is my teeth." She had false teeth. Fortunately, she died shortly thereafter. But many people linger for months or years in a drugged twilight in different measures of oblivion, pain and discomfort.

How would you like to go? I imagine it is at home, with family being there to say good-bye and comfort you and one another. I doubt if you want to linger, and linger to the point where neither you nor your family know who or what you are. Living wills, anticipatory care plans and granting power of attorney ahead of time, all help people who have lost cognitive ability.

There are 13 hospices in Scotland, two run by Marie Curie and the others independent charities. They vary in size from eight to 30 beds and provide outreach palliative care. On average, they cost about £3m a year to run, with just over half being raised from charitable fundraising efforts and the rest from NHS Boards. Volunteers are mobilised in a variety of roles and hospice staff educate and train staff in the NHS and in care homes. Each hospice has an ethos of supporting people to maximise their quality of life during the time they have left. As the population ages, more palliative care will be needed.

In 2008, Audit Scotland reviewed palliative care and commented:

> **"NHS boards commissioned £17.3 million of specialist services from the voluntary sector. The voluntary sector also contributed £26.2 million to the delivery of specialist hospice services in 2006/07… the majority of specialist palliative care beds (250 beds) and 72% of day care places were provided by voluntary 'hospices'."**

These figures apply to specialist palliative care – a significant level of palliative care is provided by GPs, as in Nairn. Hospice and palliative care

are mainstream activities led by the voluntary sector with support from the NHS. The few charitable beds (250) available all year round are in marked contrast to the 40,000 people who die every year.

In the Netherlands, there is another approach which sits alongside palliative care. "My sister had cancer; it was one of those awful cancers that was eating her up and causing great pain," Riki van Overbeek told me in Utrecht, adding, "The doctor discussed with her and with us, her family, the possibility of an assisted death. We were all thinking about it when, one night, she died in her sleep."

Since April 2001, doctors in the Netherlands who perform euthanasia are not liable to prosecution provided they follow the prescribed procedure and report death by non-natural causes to the authorities. The due care requirements stipulate, among other things, that the patient's request to die must be voluntary and well considered; their condition must be hopeless and the pain unbearable. A second doctor must be consulted and the euthanasia/assisted suicide must be performed with due medical care. The physician's action is then examined by a regional review committee to determine whether it was performed with due care.

In 2001, there were 3,500 cases of euthanasia, representing 2.5% of all the people who died. Apparently, in practice, much depends on the attitude and behaviour of the doctor. Some doctors openly discuss the option with patients and family, while other doctors never raise the matter.

We do not have voluntary euthanasia in Scotland. Framing laws around such a personal matter and doing it in such a way that it protects the vulnerable from abuse would be a test for legislators. Is it worth the enormous fight and moral polarisation? Perhaps we ought to continue with the unspoken bond between some doctors and patients on administering morphine to deaden acute pain and increasing the dose to advance death.

We ought to talk about what it means to have a good death.

A picture forms

This chapter started with the question "what can 'they' the government, local authorities and the NHS do to make life worth living for people as they get older and older?"

The dominant political mindset is one of a railway signal box with long-handled levers and a health structure still dominated by acute conditions, big hospitals, consultants and Royal Societies and a care structure running

along a parallel track.

By putting the older person at the centre and working with a different mindset – how can we help older people in their independence and health? – we create a new paradigm. But if older people who need support and care are to be empowered, that can only happen if workers and carers are also empowered.

The examples above indicate the way we should be going. The challenge is to use the talents of so many committed and gifted people, in Scotland and elsewhere, to rebalance our approach to health and well-being across life, from birth to death: to make the social contract work.

Perhaps what we are looking at is a new health and care dance. To learn a new dance, both partners need to learn and practise together - on one side the statutory organisations and on the other side, individuals and communities. This is not about a smarter more efficient dance, but a different set of steps.

The next chapter considers in more detail what individuals supported by family, friends, neighbours and third sector organisations can do. Moving from one order to another is a challenge:

“There is nothing more difficult to carry out, nor more doubtful of success, nor more dangerous to conduct than to initiate a new order of things. For the reformer has enemies in all who profit by the old order and only lukewarm defenders in all those who profit by the new order.”
Machiavelli, The Prince

But this is a challenge, we all have to accept.

Chapter 6: What can we do individually and collectively?

Third framing of the challenge

Ageing is a normal part of life. How can each person, family and neighbourhood, the third sector and the government rise to the challenge so that people have a good life and a good death?

In the last chapter we looked at what the state (the government, local authorities and NHS) could contribute. But what about the rest of us? How will we all take more responsibility control over our health and care?

The following map helps us to see what has to be done:

Map: A Life Worth Living	
I – Personal values and views • Mind set • A life worth living • Connected, isolated, not bored • Look after self • Look after others • Purpose and belonging	**IT – Objective** • Good diet, exercise, alcohol consumption, safe housing • Different acute conditions • Ability and disability • Care system performance outcomes
WE • Building neighbourliness • Community capacity • Self-directed care • Social and cultural norms • Participate and volunteer • “Normalise” old age	**THEM** • Government UK and Scotland, NHS and local authority policy • Make a priority or not • Policy and programme reality • Balance between prevention, early intervention, acute services and care • Support to keep people in community

Each quadrant expresses a different aspect: the “I” is subjective – what do I think, believe or feel? “IT” is objective — I drink too much alcohol, I have a long-term condition, my income and savings are moderate. “WE” is about our norms – what will happen to my elderly mother? Will she play an active

part in a circle of friends and family or be cut off and lonely. “THEM” is the state – the Scottish Government, local authorities and the NHS.

This map helps us to see the balance of elements in our world. It breaks a big issue down into more manageable and intelligible chunks. Implicitly, it prompts questions about how one quadrant relates to another, most specifically what is the “it” which “we” want and what is the “it” that “they” say and do.

This map helps us further investigate the three key questions raised earlier:

- What will communities and voluntary organisations deliver?
- What will individuals do more for themselves?
- How can the government and voluntary organisations help in reshaping expectations and supporting transformation?

If we are to get the balance right between what the state does and what we ourselves do individually and together, people need to be better organised and heard.

On the surface, the government recognises the necessity of shifting the balance. Its main health and care policy document on the demographics of ageing “Shifting the Balance of Care” indicates that this is a two-stroke engine: in the first stroke it shifts the setting from hospitals to the community and in the second stroke from professional services to self-help and friends, neighbours and relatives supporting one another. But it is one thing to say that on the packet and another being able to make that happen in practice.

Sceptics might say that this is the state washing its hands of its responsibilities. It is simply the Scottish equivalent of the Prime Minister’s much criticised Big Society.

Perhaps. But we ought to remember that people who are ageing have told us that they want a more individual sort of care, in their own homes with familiar people around. They want to get on with life, are wary of hospital and only in absolute extremes would they live in a care home. They want to die in a dignified way.

Our current dominant model of health and care, with its industrial process and large-scale contract commissioning, cannot meet this more humane and softer requirement. We need to find a different approach that complements the more acute medical model.

A good test is this: if the pattern of increased public spending had continued to grow would we want to continue buying health and care in the way that we do? The answer is "no".

As well as the problems with the dominant model of health and care for the elderly, we also have financial collapse, a sovereign debt crisis and the looming fiscal squeeze caused by fewer hands in work and more people claiming pensions, health and care costs.

Even in these circumstances, it is difficult for the government to give away its sweeties or its responsibilities. Politicians like to pull levers and senior clinicians and managers are rewarded by the size of their budgets and the number of people they manage.

Can the government engineer an empowering of people? The state is such a significant player and, as such, it needs to make decisions about the shape of future health and care. It is the prime mover and it needs to act. Once the government gives a steer, the third sector can do what it does best: mobilise people, advocate, organise the community and match volunteers to needs, deliver services and run social enterprises. The third sector needs the government but if the government and wider society is to shift the balance to a more normal and personalised health and care way of life, the government has an ever greater need for the third sector.

Individuals will act and make choices but much of their effort and effectiveness will come about by working together. Today, the treatment and experience of the person diagnosed with cancer is significantly better than it was 20 years ago. Medical science has helped but so have the cancer charities which carry out research, provide Macmillan nurses and provide feedback loops from patients to service providers. Concern and sympathy for cancer patients was channelled through third sector organisations and what has happened for cancer will now, most likely, occur for dementia.

What is the third sector and what roles can it play in advocacy and dialogue with "them" and how will the "I" and the "we" work through the third sector, social enterprises, community, volunteering and voluntary organisations?

What is the third sector?

Three characteristics mark out third sector organisations from private companies and public organisations:

- They are led through their committee of management by volunteers
- They are not for private profit – there is an asset lock that prevents profits or assets being transferred for personal gain
- They are not part of the state and not open to being directed by the state

In Scotland, there are around 45,000 voluntary organisations; many of them are tiny and some are of significant size. Collectively, they employ 140,000 people through an array of charities, housing associations, industrial and provident societies, friendly societies and, more recently, through Scottish Charity Incorporated Organisations. Their total annual turnover is in the order of £4.4bn. Organisations contracted to deliver services to people with mental or physical care needs are the largest third sector employer.

Most are doing very good work but they recognise a potential trap. The more their organisation is defined by large budget contracts, the more they become yet another undifferentiated provider of services competing on price. And once price is all you compete on, it is a race to the bottom. In a way, some or parts of these organisations have drifted or been induced away from their core values, and have eliminated the added value of personal contact and familiarity, mobilising volunteers and raising extra income. They have slid from "we" closer to "them" by being tied into a strict contract culture.

This is not a very satisfactory arrangement for clients or "them". Big care contracts, by their very checklist nature, cannot be sufficiently flexible to meet people's varying needs nor do they address the need to orchestrate and build capacity in the neighbourhood or community.

There are lessons to be learned from the 1980s when the last major category shift in care took place, from long-term institutional care to care in the community. Over several years, a loose coalition of interested parties came together to form the Scottish Care in the Community Working Group. Perhaps SCVO ought to make a start by convening a "Scottish Health, Care and Dying Working Group".

Numbers do not adequately capture the advocacy, representation, involvement and range of services carried out by third sector organisations and volunteers.

The United Nations identifies four categories of volunteers:

- Self-organising, like the Ramblers Association or Alcoholics Anonymous
- Formal volunteering, like WRVS and the 5,000 volunteers who help with driving or tea trolleys at hospitals each week
- Civic involvement, community councils and community groups, housing association board of management, organising summer fetes and running community facilities
- Campaigning and advocacy, from anti-Iraq war demonstrations to agitating for more public benches and 20-mile-an-hour traffic zones

Of course third sector organisations vary, but the sector, as a whole, tends to have the following characteristics:

- Values: it sees people in a holistic way and gives a voice to people who are hard to hear and reach; there is usually a bond of trust
- Delivery: it is good at mobilising and empowering people and in changing attitudes
- Innovation: it takes risks, is nimble and flexible, performs a monitoring or watchdog role and has a variety of financial models that usually involve private as well as public money
- Experience: polls show that people trust voluntary organisations and volunteers

Here is a picture of good practice happening now in the third sector that has implications for the future. The examples chosen come with a profound apology to those people and organisations not mentioned.

Advocacy and feedback loops

Breakthrough Breast Cancer has made a major improvement to patient involvement and breast care services. It has combined a national standard of service with a “Service Pledge” in each hospital and a team of volunteers trained to interview and prompt patients on their experience of breast cancer treatment. Results are collected, carefully analysed and matched against the national standard. In analysing the results with professional staff, the aim is to see what has been done well and what can be improved.

Can this approach be used more widely in dealing with different health conditions? It requires willing professional participants and hard clinical standards against which to monitor.

Can this quality circle approach be transferred into care of the elderly? It is much harder as care is more nebulous and changing and thus not easily matched against a national standard. True, but not a sufficient reason for not taking this further. Almost everyone I speak to tells a horror story about the hospital and institutional care received by an elderly person, usually a parent or in-law. What they do, even the most resourceful and best connected, is scream privately. They are not vindictive people – they want to improve the system for their loved ones and others.

Advocacy and feedback loops like the breast cancer example, are a success through the active cooperation of a third sector organisation, volunteers and NHS staff.

Dementia and anticipatory care

Worst nightmares and dementia sit comfortably together. Dementia contributes 11% of all years lived with a disability, more than strokes, cardiovascular disease and cancer. Around 82,000 people in Scotland have been diagnosed with dementia (with many more going undiagnosed) today, with the expectation that by 2030 it will double.

Dementia care has two hurdles in Scotland: stigma and a widely-held perception that nothing can be done. In the words of Henry Simmons, Chief Executive of Alzheimer Scotland, "Sadly, at present, there are few clinical treatment options for dementia, none of them treat the illness but will delay some of the most severe aspects of the symptoms. In the absence of any imminent scientific breakthrough, dementia must be treated as one of the most significant social care issues facing the country, at present we estimate a cost of £1.7 billion per year; £700 million of that support comes from families and carers."

Once there are concerns or symptoms, early intervention is the best approach to arrive at an accurate diagnosis before compassionate communication and helping people cope, control their lives, live well with dementia and plan for the future. Evidence suggests that good post-diagnostic support can help delay admission to formal residential care for two to four years. Introducing a new model, in a coherent way across Scotland, would cost £8m. This would provide a small multi-disciplinary team each working with 150 people each year. To pay for itself, this would only require each person to have a two-week delay in admission to a care home.

For over a year, Alzheimer Scotland has been running a pilot programme with Ayrshire and Arran Health Board and North, South and East Ayrshire Councils to use personalised care to assist Altzheimer sufferers and their carers. Already, they have found that it reduces levels of stress at home, people stay at home longer and that it goes some way to avoiding crisis. The last word goes to Henry Simmons: "The message is that we can do something and we can cope but we need to act now."

Volunteering

Most care is provided on a voluntary basis by partners, family members and friends. They do this out of love and a sense of responsibility. Formal volunteering will grow as the population ages and so it should. As more people who are fit and healthy retire, it is good for them to volunteer and good for the people they help. Volunteering provides an array of benefits: people do best when they are connected, have relationships, are involved, have meaning in their lives and are taken up by the flow of an activity. Relationships cannot be bought with money but modest amounts of money can help to set up the structures that orchestrate the volunteering.

The goal of the WRVS is to help older people get more out of life by providing practical support through the power of volunteering. Every day, around 6,000 elderly people helping in hospitals, driving people to appointments, providing meals on wheels (though contact on wheels might be a better description) and befriending people who feel isolated and cut off.

There are hundreds, if not thousands, of organisations across Scotland which galvanise volunteer effort. Most observe that it works to the benefit of the volunteer and the service user(s). The scope for formal volunteering as well as the neefd for volunteers is growing as our populations in retirement grows.It is worth noting that a key to positive relationships grown through volunteering, is finding mutual interests be it dogs, dominoes, books or walking.

Scotland is rich in volunteering But this needs building on and cultivating more imaginatively.Here are two international examples illustrating how volunteering is supporting elderly people:

1. "Caring relationship tickets" or Hureai Kippu as they are known in Japan, where they have been operating and expanding since 1991, are seen as one way of managing the country's rapidly ageing population. A volunteer literally banks hours they spend helping an elderly or disabled person in their "time account". These credits can be kept for later in life

or transferred to a member of the family. Local and national government has set up a nationwide electronic clearing network. So, a person can provide help in Tokyo, and their time credits be made available to their elderly parents elsewhere in the country.

2. In the Netherlands, two major initiatives are boosting volunteering. In the last two years, a programme has been introduced for all school children between the ages of 13 and 18. They are required to do the equivalent of seven weeks' full-time volunteering during their secondary school years. Some organisations and companies offer volunteering options to people, in company time, as they get closer to retirement. Studies have shown that people who start volunteering before they give up work are more likely to volunteer once they are retired.

Low key and low tech but high impact

It is often small things that make big differences to people – not big investment or high profile ventures. For example, community transport in rural areas, often initiated by local people will compensate for the lack of a bus service. But the support often goes beyond the vehicle and into the front room, for example by making sure that older people can physically get out of or back into their houses safely and taking people to their doctor or to hospital appointments. Services like these help people get out independently, with support, and to go about their business.

Already funding is in retreat. Measuring the benefits of keeping older people connected and staving off boredom and isolation are harder to measure than miles travelled. So too with Care and Repair, which helps elderly home owners and private tenants to repair and adapt their homes so that they can live in comfort and safety. As technical fixes they may be small, but they give practical support and reassurance to people. These, and other third sector contributions, are not flash but they do represent an essential bit of the fabric that helps people manage their own lives in their own homes.

Poverty and advice

Scotland shares with the UK one of the lowest rates of state pension in industrialised countries and, despite the "Jock Tamson" mythology, one of the most unequal distributions of income and wealth in western industrialised countries. Many baby boomers are going to face their old age in poverty. Citizens Advice Bureaux combine the work of trained staff and volunteers to help people in this bureaucratic age know their rights, make the benefit regime work and navigate credit card debt and phone

contracts. As fuel prices go ever up, winters get colder and the old spend more of their time at home, the work of fuel poverty charities will become more precious.

This is just a flavour of the work that abounds in the third sector. A mechanism, a process set up by government, local authorities and health boards, is needed to capture the locked-up resource that the sector has to offer and to build on very practical examples of what works exceptionally well.

Respecting the old and cultivating the new

There can be a fetish about everything being new and innovative, which is downright silly as much of what the third sector does is solid and needs to be promoted. However, new circumstances lead to new ways of organising. Three of the world's largest companies, Apple, Microsoft and Google, did not exist 30 years ago. New third sector organisations, charities and social enterprises, will form and expand as innovative ways of meeting social need and as expression of our passion and compassion.

Here are a few possibilities:

Buurtzog has worked and spread like wildfire in Holland in meeting the care needs of people in the community and working with families and other professionals. Could this community-nursing model become a social enterprise in Scotland?

Care homes are increasingly run by private companies and, as we have seen through Panorama and Southern Cross, this is not the best business model for looking after vulnerable people. What scope exists for the third sector and faith-based organisations to run more nursing homes? Are there ways of creating new equity models where, instead of paying a weekly fee and having the same rights as a hotel guest, residents could share some of the capital costs and their estate liquidate the capital when they die?

Can the desire for a dignified death, instead of a toxic last few months, be given expression in a public discussion and campaign? It needs people, not the state, to assert that dying is "natural" and that spending 25% or more of our health care costs the way we do on preserving life, is misguided. Campaigns grow in the third sector out of deep-seated public feeling.

Can community-based housing associations examine their core business and consider the implication of a large percentage of their residents being

ageing baby boomers. What can housing associations do to combine personalised care with their responsibilities as landlords and as part of the community fabric?

What new models of shared housing and housing equity will develop as more and more young people find it hard to get a first-time mortgage while their ageing parents, with increasing care needs, live in houses too large for their needs?

New technology for old people will make an appearance through telemedicine, communications and virtual communities (Gran.net; Oldindependent.net). It is the young and the old who are online the most.

Isolation and loneliness are largely ignored in acute health care. Yet, loneliness destroys quality of life and increases the likelihood of going to hospital or into a home. Research by the Free University of Amsterdam reveals that up to one third of over 55s are lonely and around 4% are lonely to a very serious level. What opportunities does this create for the third sector in organising good morning and good night telephone trees, older people meeting in one another's homes to watch DVDs or other activities?

In conclusion, it is hard for isolated voices to be heard. Through service delivery, advocacy, social enterprises, volunteering and working in the community, the third sector hears what people want, expresses their interests and then practically sets out to put matters right. We need to move to a new balance between the essential services provided by the state and the more personal and local work initiated by the third sector.

Chapter 7: Conclusions and recommendations

It is easy to be cynical on the grounds that entrenched political and institutional interests will impede sensible change. Or to think it is all too big and unmanageable.

I have faith in our social democracy to engage with ethical and efficiency interests and reconcile personal interest with a state that does need to intervene. Beyond high politics and policy, Scotland abounds with sensible, decent people who want a good life for themselves, their children and their society.

Into this mix come the financial crisis, which started in 2008, and the challenges posed by the human and fiscal effects of an ageing population. Crisis and necessity are the agents of change. We have both.

Warm words, strategies and frameworks do not make up for implementation deficit syndrome. We need to recognise just how enormous and urgent the challenge is before we boil. And we need to act in accordance with best thinking and best evidence.

Desired change is fuelled by crisis. Next are necessity and a clear picture of what is wanted and the practical steps to get there. This is true for societies and for companies. Ageing and dying are both part of a life worth living. Expectations and actions (of individuals and the state) need to shift.

And there is already a sense of shift. The examples in this report may not yet have gathered the attention they merit or be on the scale required but they do provide practical answers and these are the answers which we need to build on.

Grand gestures count but it is often the “small” people or organisations who come up with the answers. Let me give you an example from my earlier working life.

In the 1980s, I started a company called Heatwise Glasgow which insulated houses and gave short-term employment to long-term unemployed people. We hit a sensitive spot in what we were doing, did our job well and grew and grew. By the mid 1990s, we had a core staff of 250 people and 1,000 formerly long-term unemployed people who were paid weekly and on one-year contracts.

Despite back-to-work interviews and timely and active supervision, absenteeism on a Friday and a Monday was getting out of hand. We analysed and debated this endlessly at executive meetings and set up work groups to find an answer. We got nowhere.

But the accountant took me by the elbow one day and said I should come and meet a junior member of staff who worked on payroll. She explained that our instruction to the bank to pay weekly workers on a Friday was interpreted by the bank as making a deposit late on Thursday into each person's bank account. So, on Thursdays at 8.45pm, many of our employees lined up at the hole in the wall, went to the pub and did not come in on Fridays. We amended the instruction to our bank. Within a couple of weeks, our absentee rate plummeted.

The recommendations and examples given in this paper may seem small. They are not. A finger pointed in the right direction is worth much more than a lot of activity heading the wrong way. Small, practical steps that are already working can grow in significance.

Recommendations for the Scottish Government and NHS

1. See what is in front of the nose

1.1. From Nairn, see how **primary health care assesses and knows its patients**, creates anticipatory health plans and works with the local community to attend to needs at the local level. It stops the escalation to consultants and the big hospital and premature referrals to nursing homes.

1.2. By extension, be confident and strong enough to **support NHS Boards**, when they have done their homework and consulted with the local population and decide that the **best course is to close a hospital** and use the resources to support health and care in the community.

1.3. From North Lanarkshire and the Borders, see how the **local authorities have consulted with the local population and put in place personalised care packages** which give people greater control and make large scale industrialised contracting a thing of the past.

1.4. From the Buurtzog community nursing model in Holland, **give community nurses the scope to make sensible decisions** once they have listened to and got to know their older people, doctors, family and neighbours. Let the professionals make the decisions. Free up community nurses and resist "control freakery". At the

moment, the Dutch community nursing model would not be allowed in Scotland as the nurses would have to be direct NHS employees. The Government should **support, within the social enterprise model, establishing Buurtzog** in Scotland.

1.5. From introspection and common sense, recognise that there are worse things than dying. **Expect GPs to have anticipatory care plans, advanced directives and risk registers for older patients.**

1.6. **Consult the public on dying** and create charters on dying like the one adopted in the north east of England.

2. Locality planning: budgeting and decision making at a local level

Locality planning involves public sector organisations working with local communities and community organisations to:

- work out what local communities need and want
- change the way that service providers work
- deliver services that meet communities needs better
- argue the case for additional resources, where they are needed

In the past few years, there has been a growing desire to fill the democratic gap around health boards. The sentiment is worthy but needs retuning: the big gap is the lack of local sensitivity and local responsiveness. In the first set of recommendations, the common thread was about getting closer to the older person. A health board is a very large, centralised institution and it is asking too much of it to attend, as the new demands of ageing health and personal care require, to local needs and close work with other local players.

To be clear, locality planning is not about big structural changes which take years to implement. Locality planning is about encouraging **collaboration** (which is already happening in many areas to some degree) **and back it up with local budgets and the ability to make decisions at a local level across local authorities, health and the third sector.**

There are doubts about the meaningful role played by Community Planning and the scale on which it operates. Pilot work has been conducted on an Integrated Resource Framework on local decision-making for health and social care. In carefully examining the results of the pilots, a clearer model for locality planning should emerge.

3. Measures: at a population level measure quality of care for older people

Key performance measures and targets drive people in private and public organisations. If there is no data, then there is no problem. Waiting lists times have topped the health list for a decade or more oushing other issues lower down the agenda.

Talking Points – the outcome-focused care assessment approach developed by the Joint Improvement Team has gathered management information about feeling safe, being engaged and feeling better. But this needs to go further.

We need measures that tell us about progress in looking after the health and care needs of older people and the quality of their death. No single measure can do the job. Increased longevity could mean that more people are prospering or that they are just hanging on through drugs and drips. Decreased unplanned hospital admissions for older people could indicate that people are being looked after in the community or that their needs are being ignored.

In order to identify what is missing as people get older, **at a population level, measure met and unmet need linked to a quality of life survey.** This quality of life survey should be **complemented by a survey of the family and friends of people who have died**. The aim would be to measure the quality and sensitivity of the health and personal care and to create feedback loops for the staff involved.

4. The NHS and the third sector learn to dance

NHS boards manage big budgets and large numbers of people; inevitably processes become industrialised and commissioning becomes clunky. Third sector organisations are, usually, smallish in nature and work in a more personal way. NHS boards have big fish to fry and buyers have rules to follow. **Third sector organisations need to find a way of presenting the benefits and opportunities to different parts of health board structures. New steps on both sides need to be learned and practised.** Is it possible to examine the role of the third sector in the context of the current work to fuse health and care in NHS Highland and similar initiatives in other boards? Can the health Minister ask for commissioning and tendering rules to be inspected so that they are “third sector friendly”?

5. Long-term care insurance

Responding effectively to the effects of ageing and multiple chronic conditions requires a major shift in health care from hospitals to home care. Ensuring that continuing care is adequately funded and exists as a complement to appropriately-sized hospital and medical care, requires a specific fund: a long-term care insurance. A public insurance scheme is an equitable prerequisite for funding the growth in care needs of the population as it gets older. Our other options are to let need go unmet or to decimate other forms of public spending.

The Dilnot Commission recommended an insurance system. Rejean Hébert (see above) has spent a year in Europe reviewing the different national approaches already being adopted. For example, in France, the Personalised Autonomy Benefit (APA) and the linked National Solidarity and Autonomy Fund are financed by a tax on employers, partially offset by cancelling a national holiday and a tax on income.

If Westminster supports a public insurance system, good. If not, this could be the opportunity for Scotland to use its tax varying powers.

Recommendations for local authorities

1. Total Place[3]

Under current organisational arrangements for social and health care, resources are wasted through duplicate and overlapping services. Occupational therapy services, for example, have been provided by both the NHS and local authorities for decades as separate and distinct services, when service users and tax payers would have been better served by one single integrated OT service.

Total Place provides the opportunity for public providers, third sector organisations, service users and carers to jointly assess needs in local areas and redesign services to fit local needs rather than organisational boundaries.

Local authorities and health authorities should, therefore, **identify the total amount of resources they expend on care service for the elderly in defined local geographical areas. Following the Total Place approach established in the English pilot areas, they should**:

3 Total Place is an initiative which looks at how a 'whole area' approach to public services can lead to better services at less cost. It seeks to identify and avoid overlap and duplication between organisations in order to improve services and efficiency at local and government level.

1.1 Audit the totality of this expenditure for waste, overlap and duplication

1.2 Redesign the services they provide on the basis of one integrated model, actively engaging with service users, carers, and local voluntary and community groups in that redesign process

2. Kinship care

Elderly people and people at the end of their lives want to be cared for in family and domestic settings by people they know, love and trust. Formal care offers much to support elderly and infirm people who are in need of support, but ultimately cannot provide the intimate and personal support people desire in the lonely and distressing times of infirmity and illness, and at the end of life itself.

The need and preference for care in domestic and family settings also exists amongst other service users, and it is reasonable to suggest that many more family members and partners would be prepared to provide such intensive care if they had the resources to enable them to do so. This means that more support for carers is required, including payment.

Local authorities, therefore, should **reduce the level of formal, professional care support and intervention in order to free resources for redirection into a much more extensive provision of kinship care.** Not only would this mean that care could be provided where elderly people want it most, in family and domestic settings, but it would also represent a substantial transfer of financial resources into low-income families in return for significant benefits in caring for the elderly. Formal professional support and intervention could then be targeted to people with complex and difficult needs, and in providing advice and support to kinship carers.

3. Economic and business development

In the changing landscape of public sector retrenchment and contraction, it is essential that businesses, social enterprises and voluntary organisations fill the gaps previously occupied by the public sector. The economic and business development functions within local authorities **should begin to support the growth of such enterprises, and also to ensure that the appropriate skills exist within local labour markets.** This will require effective joint working involving education authorities, further and higher education sectors, and economic development functions. Local authorities should:

3.1 Actively promote the formation of new businesses and social enterprises, and encourage growth in existing enterprises in the care sector

3.2 Promote the culture and skills development necessary for ensuring an adequate and appropriate labour supply for the social care sector in the years to come

4. Service redesign

Given the significant changes relating to demography, care requirements, and the shifting balance of responsibility from the state to the individual in meeting the costs of care, **local authorities and their health service, the third sector and other partners should review and redesign services and support for older people.**

Already, the leading local authorities are anticipating these changes by undertaking fundamental reviews of these services. Such reviews should be Scotland-wide, specifically with a view to reconfiguring the resources devoted to:

- accommodation with care
- home care
- short-term rehabilitative care for people leaving hospital
- day services and day hospitals
- preventative services, to help those with low level needs to maintain their health, well-being and independence
- social work customer contact services and arrangements

5. Consulting and engaging

The local authorities which are ahead in preparing for increasing needs and declining resources underpin their services and future plans with good and effective engagement with service users, carers and third sector organisations. **All local authorities and health authorities should establish effective ways to listen to and communicate with people who are using, and who will use, their services.** Personalising care services cannot be a one way conversation. To be successful, it depends entirely on the commissioning body, whatever that might be, listening to, understanding and respecting the needs of the service user in providing and planning for their needs.

Recommendations for the third sector

1. A cohesive third sector

At the moment we have 45,000 third sector organisations flying in free formation. How can a health board or local authority know and negotiate with the third sector? Everyone loses out through a failure to share intelligence and or flex muscle in asserting the need to move to a more personalised model.

Of course, there is a contradiction in this: the need for more centralised coherence in order to advance an approach that is more local and personal. But how else can we progress? No single organisation has the answers and they all have a role to play.

So much of the democratic process and executive decision-making is made up of lobby groups and charm circles - rather than listening to what is intrinsically a sensible argument or a persuasive case. There are umbrella groups within the voluntary sector to represent care, health, volunteering, or different parts of the country. Good or very good as these groups are, they are caught up in fighting their own fires and have usually been set up in structures which run in parallel to the statutory organisations.

The third sector needs to jump the tracks and find a coherent way of making the collective case for “I” and “we” and help to design initiatives and processes which reflect where we want to get to in the next 40 years - not to perpetuate where we have been for the last 40.

Nothing is ever going to be perfect. But following the rule that you get 80% of your value from 20% of your work or investment, **a group of voluntary organisation leaders across health, care, dying and volunteering should get together informally to investigate what is possible. An organisation like the Confederation of British Industry in Scotland should be formed.** Not everyone needs to join, and it would speak for its members not for everyone. A “closed” company, with a five to ten-year life span, would concentrate effort on shifting the balance and set aside fears that it would compete with members. It could be **funded by member contributions and an endowment from the Scottish Government Change Fund.** It could either be a new organisation or formed around an existing organisation like the Long Term Condition Alliance.

Such a federation would work with the desire for a more humane and personalised approach to health and care of the elderly, death and dying and find a way to talk with government, health boards, COSLA and local authorities. There is common ground as third sector organisations struggle

with reduced funding and recognise the need for a new mindset and model of localism and self-directed support.

The third sector, the government and NHS boards need to think about how they engage. GPs who feel professionally comfortable about making a referral to another part of the NHS need to feel confident about referring people to a community organisation. How can a commissioner of services in a local authority gain the trust to work with, say 300 personal carers, with a regulatory body and the Sun newspaper looking over their shoulder for the first juicy story? Southern Cross, and its sad shaky background, shows how important sustainable funding is when entering into long-term commitments for care.

2. Helping people to help themselves

The scale of the third sector contribution and how it mobilises people needs to grow. Good practice in the third sector is isolated and atomised. Third sector organisations need to get to know and work with 14 health boards and 32 local authorities, often in competition with one another and private sector providers. The onus ought also to be on health boards to find out about good practice taking place in their patch and set about scaling up such preventative work. But if that, as is the case at the moment, is only happening by happenstance, a more proactive approach is needed.

2.1. A two-step approach is needed. Firstly, a framework or process should be created, most likely in conjunction with the Joint Improvement Team and COSLA, to **evaluate and understand the nature, range and scale of the third sector contribution** across Scotland.

2.2. Secondly, **a process should be initiated to upscale, replicate and support the spread of good third sector practice**. This would involve working across professionals in health boards, GPs and local authorities. This could be a natural extension of the good practice work that JIT is currently undertaking with public services. In chapter 7 above, a range of good third sector practice is set out. In practice, what support can be put in place to open out and upscale third sector work palliative care, community nursing, dementia and volunteering?

3. Reflection within the third sector

Third sector organisations cannot count on a future on the strength of their hearts being in the right place and the argument that “it’s aye been”. Tomorrow is not the same as yesterday. Enable Scotland, one of the largest caring third sector organisations, has come to the conclusion that

the future of care is on a personalised model with clients holding and managing their own funds. As a large company previously reliant on major care contracts, this mind shift has had a profound effect. Jo Armstrong, chair of Enable, explains how this has meant ripping up the previous business model and reducing and significantly restructuring the staff team and how it works. For Jo, there is nothing sacrosanct about the third sector and its contribution. The third sector has to have decent values, deliver a good service and be a good advocate.

Hard as it has been for Enable to change its mindset and then its business model, this is exactly the course it is now on.

From volunteering to managing health conditions to personalised care, the implications for third sector organisations are profound. **Some serious reflection is needed.** This may be hard for so many third sector organisations at this time of financial crisis but perhaps, by seeing themselves in this new context, they can find a new role which enhances their core values.

4. One place

It has already suggested that the NHS and the third sector should learn to dance together. Recommendation 3 above suggests how the NHS and the third sector might work together. This recommendation is about **focusing at a local level and seeing very practically what can be done. A demonstration of best third sector practice and best experimentation should be tried out and evaluated in one place**. A qualitative evaluation could be carried out looking at the satisfaction and happiness of the different stakeholders and the effects on costs.

This would require a willing, coterminous local authority and health board to identify a suitable area, town or community. The idea would be to secure funding for, say five years, to enhance what the sector does and compare results against a similar area where there has been no enhanced support. **If an investment of £3m were made each year for five years, this would make the third sector a truly equal partner** and change the dynamic of the relationship, making the third sector an equal partner. In turn, the third sector would need to prove in the evaluation that what it was doing was cost effective. In the terminology of today, this would be like a social impact bond.

Investment support and interest from the Scottish Government would be a precondition to help iron out potential process or funding glitches and also to engender an interest in the outcomes. Learning would be provided

on processes and how people from different sectors and professional background and volunteers plan and work together.

Although this section is dealing with recommendations for the third sector — when it comes to “one place”, the government, local authorities and NHS could take advantage of the test ground to try out anticipatory care planning and advanced directives for all older people.

5. Following up the recommendations

5.1 SCVO should promote discussion and forums on the underlying issue and how the third sector should respond.

5.2 SCVO will table this document and its recommendations at a future Ministerial Strategic Group.

End piece

We are not much closer to finding cures for cancer, heart disease and strokes and we have still to find a way of delaying the progression of Alzheimer's. Our main technical progress is finding ways to marginally extend the lives of the very old and ill. But bodies wear out and die. And life expectancy will level off in due course.

A large slice (around 25% and growing) of your health spend and, that of the entire country, goes into the last few months of life. But, when we no longer enjoy spring, smile at our children, tease our partner or enjoy our favourite piece of music, should we, as gracefully as possible, bow to nature and move on?

Can we confront death and talk more about a life worth living and a dignified death?

Through the third sector, there is a way to shift the balance back to people. But we need to act quickly. The frog is getting warmer and warmer. There is still time to for us to jump - both to care for old people and also to rebalance the social contract to the living and the young. I have a feeling that many people share this sentiment.

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