

**National Framework for Service Change  
in the NHS in Scotland.**

**Self care, carers, volunteering and the voluntary sector:  
towards a more a collaborative approach.**

**May 2005**

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## **Vision: towards a more collaborative, empowering approach**

Scotland's Health White Paper of 2003 was entitled 'Partnership for Care'. A central theme running through the White Paper is the need to work in partnership with patients, carers and volunteers in delivering health care.

This theme provides a solid foundation for looking forward to ways in which patients, carers and other 'non-state' providers can be actively encouraged to become co-producers of healthcare. Such initiatives will bring

- benefits for patients
- benefits for carers
- benefits for volunteers
- benefits for NHS

The National Framework is a framework for service change in the NHS in Scotland. However the National Health Service is not the whole of the health care system.

The NHS is part of a wider whole system of health care. Other major elements of the health care system are the people experiencing ill-health themselves in the form of self care and the carers (unpaid, most often family members) of people with health problems. The wider whole system also includes people who assist in providing health care as volunteers and the professional voluntary sector.

It is impossible to quantify precisely the contribution of these other major components of the health care system. The boundaries of 'self care' are difficult to define. Actions to deal with ill-health shade imperceptibly into everything a person does to maintain a 'healthy lifestyle'. However one estimate is that over 80% of all medical symptoms are self-diagnosed and self-treated without professional care. (Sobel, 2003) It has been calculated that the economic contribution of unpaid carers is equivalent to the entire budget of the NHS (Carers UK, 2002)

*The challenge to the NHS is to work in collaboration with and help maximise the potential of these major co-producers of health and health care. What we must work to get away from is a health service which attempts to deliver healthcare to patients regardless of what they themselves can contribute and without involving and supporting their carers and other non-statutory providers as fully as possible.*

## **The context.**

Each of these aspects of partnership working will have their own specific developments and drivers for change. However it is perhaps worthwhile sketching out some of the factors which are of relevance to all these themes and which have brought them increasingly to the fore in the development of healthcare policy.

In terms of more general policy strands there is a powerful school of thought aimed at increasing the degree of 'personalisation' of public services whereby the user of services or the patient is closely involved in designing and delivering a package of services or care which is closely fitted to their personal needs rather than being the passive recipient of 'one size fits all' services. (Leadbetter 2004; Cottam and Leadbetter, 2004).

At an organisational level this meshes with a growing commitment to move away from a top-down 'command-and-control' system in public services in general and the NHS in particular (Scottish Executive, 2003). It has been pointed out that when the NHS was inaugurated, such a command and control system was seen as being 'necessary in the short term' but that the founders of the health service envisaged a health service of the future that would be organised and delivered locally, responsive to community need and provided as part of a wider care continuum where the citizen/patient is an active and not a passive participant. (Reid, 2004)

In terms of the culture of health care, there is an increasing perception of the need to move away from a traditional 'medical model of care' involving a 'doctor knows best' attitude among staff and a passive, dependent attitude among patients. It may be that the historical, international pre-eminence of Scottish medicine and medical education may have served to embed such a traditional medical model more deeply into Scottish culture than elsewhere in the world.

However, in Scotland as elsewhere, we are seeing the emergence of a patient who is better educated and more informed, enquiring and confident than the patient whose deference to the NHS helped create a culture of dependency and paternalism. Older people's expectations in 2024 are likely to be different from today's generation. So too will the potential for harnessing these expectations to new and expanding forms of service planning and delivery where health promotion and care intervention becomes much more a negotiated and managed concord involving the individual, carers (informal and formal), communities and the range of providers.

A review of the literature on the ageing population – aptly termed the “baby boomers” - of the immediate post 1945 period and the first half of the 1960's – ascribes to these generations two distinctive characteristics: baby boomers are renowned for their individualism and liberalism. (Dorrian, 2004). While each cohort was affected by different economic circumstances as they entered the labour market it is the shared societal determinants which unites their outlook on life. In general, older people in 2024 compared with their generation of today will:-

- be persuasive in influencing policy through non-traditional political groupings
- be “smart consumers” insisting on expanding choice and commenting about its quality
- be respectful of others values and concerned with promoting diversity be aware of individual rights and responsibilities
- be physically active with an increase in disability-free years as well as living longer
- be interested in life-long learning, post full time retirement employment opportunities tailored to suit individual circumstances and volunteering.

Perhaps the most fundamental driver of the shift towards a more collaborative approach in the production of health care is the change from acute, episodic conditions to chronic disease or long term conditions as the main challenge facing the NHS. It is increasingly recognised that the management of long-term conditions is the key to effective delivery of healthcare. It is in the context of long term conditions that patients, carers and those voluntary organisations associated with long term conditions move to the fore as key co-creators of appropriate forms of care. The simple fact that, by definition, patients and carers have to live with long term conditions over a lengthy period of time makes it inevitable that they will want and be able to develop expertise in the management of the conditions in question. An NHS which is better adapted to this new environment will be involved more closely in supporting and working alongside patients and carers to help them increase their coping skills and expertise.

In the most general sense, the NHS will move away from being an organisation which sees itself as separate from society and which delivers treatment, largely according to a technological and medical model, to patients. It will become much more of an organisation which works in partnership with other players in delivering a more social and collaborative form of health care.

### **Self care and self management.**

Self care and self management cover a vast range of actions and behaviour. The range is from casual activity to deal with occasional events e.g. buying painkillers to deal with a headache to the acquisition of highly expert means of coping with and managing complex, long term conditions.

Definitions in the area of self care and self-management are by no means clear cut. However self care does tend to have a more general definition. For example, self care has been defined as 'the care taken by individuals and carers towards their own health and well being, and includes the care extended to their children, family, friends and others in neighbourhoods and local communities. Self care includes the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain well-being after an acute illness or discharge from hospital' (Dost, 1998; Royston and Dost, 2004)

Such a wide definition would include not just care which the individual provides for him or herself but also any care which is provided outside the formal system care by family and other unpaid carers.

Self management can be regarded as a sub-category of self care which takes place in the context of a recognised medical condition and will normally include a level of formal health service input often focused on patient education, monitoring of disease indicators and skills mastery. Examples would include the self-management of such conditions as diabetes or COPD usually derived from protocol-based recommendations.

There is growing evidence to show that supporting self care has a range of positive outcomes: better health and quality of life (overall life expectancy; impact on specific symptoms such as pain, anxiety, depression); improved patient satisfaction; significant impact on use of care services (reductions in GP visits, outpatient attendances, A&E visits, inpatient admissions) (Department of Health, 2005b)

People already undertake most care themselves. It has already been mentioned that over 80% of symptoms experienced are managed without seeking help from any professionals (Sobel, 2003) People use a whole range of strategies, including 'waiting to see what happens', taking rest and taking over the counter medications.

The task of facilitating and enhancing self care is thus often a task of supporting, informing and building upon what people are already doing and are motivated to do.

An example of support at this more 'general' end of the self care/self-management spectrum is provided by the Kaiser Permanente Healthwise Handbooks which are distributed to all members of the Kaiser Permanente system. The programme reports high use of the resource with improved member self care confidence and satisfaction with the overall care system (Sobel, 2003).

The role of self care was examined in the Wanless enquiry into future funding of the NHS in Britain. An enhanced role for self care and much greater levels of facilitation and support for developing the levels of self care formed part of the fully engaged scenario outlined in the Wanless Report (Wanless, 2002). This emphasis has since become part of mainstream NHS policy in England as highlighted for example in the NHS Improvement Plan of 2004.

Most recently the Department of Health has published a report on self care which outlines a wide range of different types of self care support across the entire spectrum from improving health literacy to home adaptations (Department of Health, 2005b).

In addition the report follows the patient journey showing where and how additional support for self care can be helpful at specific points in the pathway of care. For example the report highlights the importance of good self care following discharge. Information on self care should be included as part of the care plan given to patients when they leave hospital. This will help ensure that going home from hospital is a positive experience and readmission will be avoided. (Department of Health, 2005b)

Finally self care support is presented as a crucial element of the whole system of care. It is emphasized that self care support initiatives can only be successfully embedded in the care system if they are integrated into its routine business and have the full backing care professionals, practitioners and managers.

Patients themselves are potentially the NHS's most important collaborators. The more patients can be given the information, taught the skills and given the confidence to deal safely with their conditions, as well as the knowledge about when to alert a health care professional, the more they will benefit and the more the health service will benefit.

## Self-management of long term conditions.

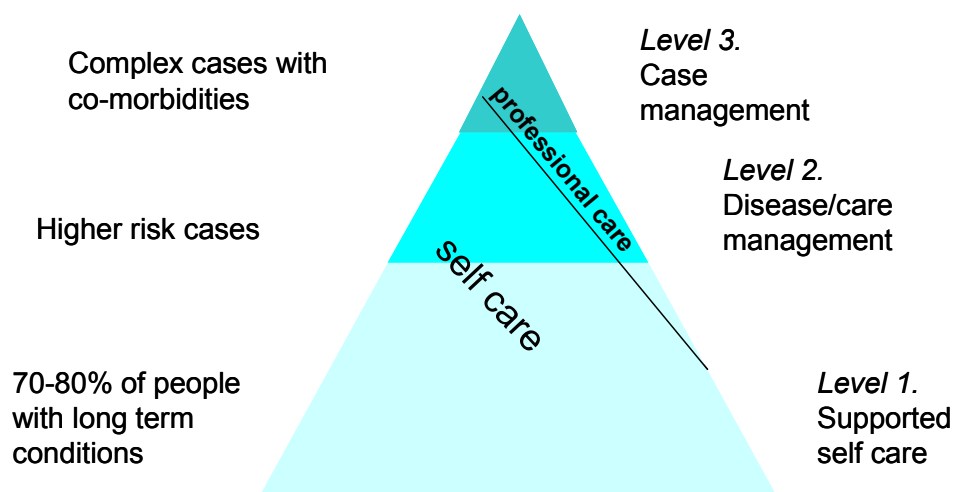
It is in the context of the management of long term conditions that self management and partnership between patients and professionals has received its clearest focus. Comprehensive models for the care and management of long term conditions are becoming increasingly influential and are being adopted ever more widely.

One of the most influential sources of this movement has been the Chronic Care Model developed by Wagner and colleagues in Seattle. From the outset, self care and in particular self-management has been a key element in the development of models for the better management of long term conditions.

A related source for improved systems for managing chronic conditions has been the Kaiser Permanente programme. In particular the 'Kaiser Permanente pyramid' has proved to be an immensely influential and useful method for conceptualising risk stratified groups of patients with long term conditions and the appropriate level of management. The Kaiser Permanente pyramid has been adapted by the Department of Health to show the role of self care/self management for different groups of patients with long term conditions (Department of Health 2005a, 2005b). Figure 1 is an adaptation of the Department of Health diagram showing the role of self care in relation to the overall model for supporting people with long term conditions.

**Figure 1.**

### ***Patients with long term conditions: self care and management***



The pyramid as a whole includes all people with a long term health condition. Level 1 is generally held to encompass 70-80% of all people with a long term condition, the appropriate model of care being 'supported self care'. Level 2 covers 15-20% of patients with a higher level of risk and who require significant specialist input – the appropriate model of care being 'disease management' or 'care management'. Finally Level 3 covers a relatively small group of patients (3-5% of the population)

who are at the highest level of risk with complex and often multiple conditions and who require intensive case management as the appropriate level of care.

Superimposed on the three levels of the Kaiser-Permanente pyramid is a line showing the relative contribution of self care on the one hand and health care professionals on the other.

As would be expected from the label 'supported self care', at Level 1 patients themselves are the main contributors of health care. The role of health care professionals is primarily one of supporting patients. The Department of Health report on self care gives the example:

“... people with diabetes have on average 3 hours contact with a health care professional and do self care for the remaining 8757 hours in a year using the advice given by professionals during the 3 hours or using skills learnt through structured self care education programmes ..” (Department of Health, 2005b)

Thus at Level 3 it is likely that the bulk of health care already takes the form of self care and the aim of the health service is to increase this proportion of such self care as well as the skill, confidence and mastery with which it is delivered.

The better self care at this level is supported, the better the chance of avoiding acute flare ups of the underlying condition which could lead to GP consultations, A&E attendances and even inpatient admissions. More fundamentally, the better the care at this level, the less the chance of a patient's condition worsening so that care needs to be delivered at a higher level.

Better and more sustainable ways of managing long term conditions will require better ways of encouraging and supporting self care among patients. Scotland is only in the very early stages of accepting the need for this transition. There is a need for a major culture shift among health care staff, patients and carers. There is a need for a recognition that better support for self care will empower patients, will improve the quality of their care as a whole and will enable a more fruitful collaboration between them and professional care staff. Producing a culture shift among staff will require training focused on attitudes towards self-management and the skills to promote it.

The body of experience and expertise relating to self care and self management is continuing to grow. Several themes are beginning to emerge as central.

**Collaboration and partnership.** In contrast to the traditional view of the patient-professional relationship in which doctors and other health professionals are regarded as experts with patients expected simply to obey their instructions, a new paradigm is emerging in which health care professionals and patients work in partnership.

“The partnership paradigm credits patients with an expertise similar in importance to the expertise of the professional. This paradigm implies that while professionals are the experts about diseases, patients are the experts about their own lives” (Bodenheimer et al., 2002)

In addition to this recognition of equality of status in the therapeutic relationship, patients are empowered by providing them with a repertoire of skills such as problem solving, goal setting, action planning and cognitive symptom management to promote both management of their condition and their lifestyle.

**Patient empowerment.** Koch et al (2004) have proposed a further model of the therapeutic relationship which takes it even further along an 'empowerment continuum', that of self-agency. In the traditional medical model, power rests with the professional. In the collaborative model there is shared power – the 'partnership paradigm'. In the self-agency model the balance of power lies with the person with the condition. Koch et al's study calls for new approaches which embrace the expertise of the person experiencing the chronic condition. A bespoke and responsive, rather than a standardised 'off the shelf' approach to empowering the patient is the focus of this new model. Empowerment occurs through learning, developmental and problem-solving opportunities that acknowledge and take account of the expertise of the individual who has the condition(s).

**Holistic approach.** Another central element in enhancing self care is a holistic approach to the patient's condition which involves managing all aspects of the illness including how best to use the care system as well as managing daily activities, their life roles and their emotions (Lorig et al., 2000). Self-management involves partnership working between the people with a long-term condition, their families and health care professionals to allow them to know and understand their own condition and the related treatments, take part in planning their own care, engage in activities that promote health, monitor their own symptoms and recognise when their condition changes. It also addresses the emotional impact and challenges of living with a long-term condition and how this can affect others.

**Psycho-social aspects.** There is a growing recognition that it is frequently not the physical aspects of a condition that most significantly influence the outcome of care but rather the psycho-social aspects. Attitude, beliefs and moods matter and behavioural interventions which recognise and support this produce better health outcomes (Sobel, 1995).

**Appropriate educational methods.** Promoting self-management must be much more than providing patients with information. There is a need for modern educational strategies which can transform a model of care based on didactic, information delivery ('telling people what to do') into a model of interactive care which focuses on self-management education by addressing attitudes, belief and moods, strengthening skills, building patient confidence and helping patients to use available resources and to form a collaborative partnership with their clinician.

**Broadening the communications spectrum.** The transmission of information and the provision of training to support and develop self care and self management need to take advantage of the full spectrum of means of communication available. Even without official encouragement, the internet is transforming the balance of expertise between the patient and the health care professional as patients often arrive at health care encounters knowing more about their condition than the professional concerned.

Kaiser Permanente for example incorporates internet material, a health handbook, taped messages on specific topics, telephone helplines and telephone 'teleclasses' into its health education and self care strategy (Valencia et al., 2004).

Their approach relates the methods used to patients' risk stratification category (see Figure 1). For patients in the medium risk category methods such as group classes and support groups are the mainstay of interventions while for those in higher risk categories there is greater reliance on intensive, individualised (one-to-one) educational interventions. Approaches to self care and self management thus form part of the wider strategy for the prevention and management of long term conditions.

A similar wide ranging approach to the promotion and facilitation of self care and self management has been proposed as part of the Department of Health in England's strategy relating to long term conditions (Department of Health 2004, 2005a).

### **Lay-led self management.**

As described by Cooper and Clarke

"In essence, lay-led self-management programmes are a conduit through which people living with long-term illnesses can develop self-efficacy enhancing skills which enable them to feel more in control of their condition. The aim is to complement existing health care provision and encourage the development of a partnership between between the patient and the health professional, in which the patient becomes the manager of the condition, learning to make the best use of the resources available to him, one of which is the health professional." (Cooper and Clarke, 1999)

Lay-led self-management programmes share several characteristics with professionally led programmes: they are evidence based; have measurable effects in terms of outcomes and include medical management of the condition. However they have additional characteristics reflecting the enhanced role of the patient: they are driven by the patient rather than the health professional; there is an emphasis on self-efficacy as a major factor in the patient's control over the condition; the programmes are lay delivered in community settings (Cooper and Clarke, 1999).

Perhaps the most influential strand of current initiatives in patient-led self management can be traced back to the early days of the self care movement in the 1970s in United States. Particularly influential was work carried out at Stanford University. An early disease specific self management program developed there was the Arthritis Self Management Program (Shoor et al., 2002). This became the basis of the Challenging Arthritis programmes implemented by Arthritis Care in the 1990s in England and in Scotland.

This is now just one of a range of lay-led self-management programmes which have been championed by patient-led voluntary organisations. (Cooper and Clarke, 1999) The Long-term Medical Conditions Alliance has played a key role as an umbrella

organisation for these initiatives. These programmes have mostly been condition specific reflecting the condition specific patient groups by whom they have been developed.

The Expert Patient Programme however is based on a generic method – the Chronic Disease Self Management Course originally developed by Lorig at Stanford University. In this approach, patients with a variety of long term conditions come together in a group to be trained in self-management techniques by lay trainers who have themselves come through the system.

In England, the Expert Patient Programme has been the basis of a major investment in patient self-management building on and in collaboration with the Living Well Project developed by the Long-term Medical Conditions Alliance. The Expert Patients Programme has been given the green light to go mainstream with the target of rolling it out to all Primary Care Trust by 2008. (Department of Health, 2005a).

### **Initiatives in Scotland.**

Scotland was an early participant in the Arthritis Care initiative mentioned above. Pain Association Scotland (see Box) has been a pioneer in Scotland in developing professionally led self-management programmes.

#### ***Pain Association Scotland***

Pain Association Scotland is a national charity that delivers professionally led pain management in the community. The overall aim is to train and maintain self management skills that enable individuals to improve quality of life and well being despite long term illness. The service is open to anyone regardless of their condition or diagnosis.

The service is provided through a network of 26 groups throughout Scotland. The groups meet in a variety of urban and rural settings in hospitals, community centres and health centres.

There is research evidence on the effectiveness of the Pain Association's approach especially when implemented in collaboration with health and social care professionals. This is reflected by the partnership they have with many of the NHS Boards in Scotland.

A notable initiative in Scotland combining elements of the lay-led and professionally led approaches to self-management is the Braveheart Project. The project was initially developed as part of the Ageing Well UK national health promotion programme. Participants are patients aged 60 and over with a clinical diagnosis of ischaemic heart disease. They participate in a series of meetings of a mentor-led support group over a period of a year. Mentors are not health professionals but individuals with experience of the same or similar conditions who undergo specific training for the project with input from a range of health and other professionals.

Sessions cover a wide range of issues relating to the management and self-management of cardio-vascular disease and the promotion of general well-being. A randomised controlled trial showed significant improvements in exercise, diet and physical functioning as well as reduction in outpatient attendances. (Coull et al., 2004)

### **Volunteer mentorship, self-help and the professional role in the Braveheart Project.**

**Mentorship** .... isn't about 'doing' things for people. Nor is it about 'telling' people what to do. It is much more about partnership, a partnership in which the mentor acts as a role model and confidant, actively guiding and assisting group members to take the steps to bring about important changes in the way they live their lives.

Braveheart was based on a mentoring model that brought together elements of self-help, patient participation, decision-making and the sharing of individual experiences and challenges in a group setting.

#### **Benefits of volunteer mentors.**

Volunteer mentors:

- have experienced the same or similar problems as their peer group which gives them credibility
- can serve as positive role models
- can offer advice and support in non-institutional settings such as community centres or day centres
- can provide vital contact with the community for more isolated people
- can expand the support system for their peers, helping them to be more aware of other community resources

**Self-help and the professional role.** Self-help offers a challenge to individuals to take responsibility for their actions and their health. It may also present a challenge to health professionals who are more used to 'doing' things for and to patients and who may feel uncomfortable about patients 'taking control' of their own lives.

Braveheart demands that professionals should look at their relationships with patients in a different way. It requires them to see themselves as educators and facilitators, setting up a cascade of information, advice and encouragement that is passed from the mentors to the patients. (Health Education Board for Scotland/Braveheart, 2003)

# Unpaid carers

## Introduction

One of the central themes of Scotland's Health White Paper "Partnership for Care" (2003) is the need to work in partnership with patients and carers.

The Community Care and Health (Scotland) Act 2002 and subsequent Scottish Executive Guidance formally recognise carers as "key partners in the provision of care" and for the first time define a legislative duty on NHS Boards to identify and support carers through the development of local NHS Carer Information Strategies.

Full partnership between the NHS and unpaid carers can bring immense benefits to patients, carers, the NHS and to local authorities in their key role of supporting carers and the people they care for. Supporting the caring relationship can lead to improved physical and mental health for both patients and carers. Health promotion for carers is critical just as it is for patients. Supporting carers helps empower them in their caring role, reduces the impact of caring on their own health and often enables them to care for longer than otherwise might be the case with the resultant benefits that brings both to the carer and the patient or cared-for person

Unpaid carers form Scotland's largest group of care providers – a careforce whose qualitative and economic contribution to health and social care provision is difficult to quantify, but is estimated at a value of up to £5.7 billion.

Although still in its infancy, the relationship between Scotland's NHS and unpaid carers provides significant opportunities for more enhanced partnerships to achieve shared national objectives: better health and care provision in the community, increasing emphasis on self care and reduced NHS and social care intervention.

This mirrors the personalisation agenda that is being taken forward in social care. The health and social care agendas are moving increasingly towards each other under the umbrella of joint working. This partnership will help shape services and support the 'unpaid careforce' to provide a vital underpinning for medical and social care in the community.

This section details;

1. Who carers are and the role they play as key providers
2. The existing context and policy framework on unpaid carers
3. The contribution of Scotland's unpaid careforce to medical and social care services, and the future of unpaid carers.
4. What carers need – to maintain their own well-being, to strengthen their ability to care and to increase the benefits to health and social care systems.
5. What the NHS can do to support carers - pathways for the development of national and local NHS carer partnerships

## **Carers: the facts**

A carer (or unpaid carer) can be defined as “a person of any age who provides unpaid help and support to a relative, friend or neighbour who cannot manage to live independently without the carers help due to frailty, illness, disability or addiction”. Many people do not recognise themselves as carers. They see themselves first and foremost as relatives, spouses, partners, parents, siblings, sons, daughters, friends and neighbours.

Unpaid carers are instrumental in supporting people in our communities both in terms of directly providing health care and in helping patients to self-manage and self care either on a short or long- term basis.

“Carers are ‘key’ partners (in the provision of care) because they are different from other partners in the care-giving system in their status and their contribution. Carers are usually the main care-providers for the person they look after, but unlike other care-providers, they are not paid to provide that care. Carers generally have a close personal relationship with, and commitment to, the person they care for. For all these reasons carers play a unique role in the overall provision of care to the person they care for, and in care in the community as a whole”. (Scottish Executive Health Department, 2003)

The role of carers in supporting the health and welfare of those they care for cannot be underestimated. A third of carers are the only support for the main person cared for. Just under a third of carers are the cared for person’s main support, either alone or jointly with someone else (ONS, 2002). Carers living in the same household as the person for whom they care provide high levels of practical and health care - 51% provide personal care, 57% provide physical help such as assistance with walking and 44% give medicines (ONS, 2002). For many carers, caring is a long-term commitment - one in five carers (21%) have been caring for someone for at least 10 years and nearly a half (45%) have been caring for someone for 5 years or more (ONS, 2002)

In addition to promoting and providing healthcare, carers help to promote independence, prevent or delay admissions to hospital or care homes and facilitate early and effective discharge from hospital. The vital contribution that carers make to the individual they care for cannot be measured in monetary terms alone but it is widely recognised that carers reduce hugely the amount of caring input that social services, NHSScotland and other agencies need to make. It is estimated that carers save the Scottish economy over £5 billion a year, almost equalling the cost of providing NHS services in Scotland – an average of £7,500 per carer (Carers UK, 2002).

There is evidence that caring can affect carers’ own health and that a carer’s own health is increasingly at risk as their caring responsibilities increase. A carer’s age will also impact on their ability to care without placing strain on their own health. Female carers with greatest caring responsibilities have a 60% higher chance of experiencing distress than non-carers; the risk of distress increasing with the intensity of caring (Hirst, 2004). Carers in Scotland providing high levels of care are a third more likely to suffer ill-health as non-carers. Nearly 60,000 Carers in Scotland (out of an estimated 600,000) say they are in poor health (Carers UK, 2004)

Many young carers aged between 5 and 18 are twice as likely as their peers to suffer from poor mental health. Studies show that young carers have high rates of utilisation of health services compared to peers when matched for age, gender and levels of deprivation (Armstrong, 2004)

When a caring relationship breaks down, often because unsupported carers can no longer cope, this often results in the admission of the cared-for person, the carer, or both to hospital or local authority care. This is particularly true where older carers are caring for elderly spouses, partners or friends. There are clear implications for individuals when the caring relationship breaks down. There are also cost implications for both the NHS and social services. In addition to the cost of treating the carer's own ill health, the state would have to pick up the cost of caring for the sick or disabled person if the carer is unable to continue caring. It is therefore in the interests of Government and the professional and statutory services to support carers as a means of promoting and safeguarding the well-being of individuals and, as a secondary but key benefit, reducing overall pressure on statutory resources.

### **Carers: The statutory and policy framework.**

“Supporting carers and involving them in the partnership of care is not a new or separate element of the Scottish Executive's social care and health agenda. Caring for carers is an integral part of wider policy approaches which are shaping the way that social care and health services are being delivered.” (Scottish Executive, 2003).

Key policies aimed at supporting carers and empowering them in the partnership of care and which specifically have an impact on the NHS include:

- Joint-working between local authorities, the NHS and the voluntary and private sectors under the Joint Future Agenda
- Single Shared Assessment – requiring increased carer awareness by NHS staff
- NHS Patient Focus and Public Involvement
- Development of new hospital discharge protocols
- The requirement by Health Boards to develop Carer Information Strategies in partnership with local authorities
- The development of Community Health Partnerships

Legislative rights for unpaid carers have been in place since April 1996 under the Carer (Recognition and Services) Act 1995. This gave regular and substantial carers the right for the first time to an assessment of their support needs, as part of an overall assessment of the cared for person's needs.

1999 saw the launch of a UK National Strategy for Carers entitled “Caring about Carers”. This was followed by the “Strategy for Carers in Scotland” published in November 1999. Central to the Scottish ‘Carers Strategy’ was a quadrupling of resources to local authorities to provide services that support carers. Resources under the Carers Strategy and separate and additional investment in short break

services (or respite) have seen the total resources available to authorities for supporting carers rising from £5 million a year across Scotland in 1999-2000 to £22 million a year by 2004/2005.

The Community Care and Health (Scotland) Act 2002 came into force in September 2002, improving the legislative rights of unpaid carers. The Act places new duties on local authorities in relation to carers but also places duties on the NHS in a fundamentally new approach. The Act provides carers, including young carers, for the first time with an independent right to have their support needs as a carer assessed by local authorities, or other agencies under a Single Shared Assessment process, irrespective of whether the cared-for person has a needs assessment.

The 2002 Act requires local authorities to notify carers they encounter in their day to day duties of their potential right to an assessment. This applies to local authorities in general not just social work services in particular. Local authorities must also take into account a carer's contribution and views before deciding what services to provide for a cared-for person.

The 2002 Act recognises the important role of the NHS in identifying and supporting carers. The Act will ensure that NHS Boards develop and implement a Carer Information Strategy, in partnership with local authority social work departments and local carers' groups. Strategies should ensure that all carers are identified and provided with targeted information at their first point of contact with the NHS, including information on their legislative rights. Strategies should also ensure that carer awareness is mainstreamed into the day to day activities of NHS staff at all levels, including contracted staff. NHS Boards will be required to report regularly to Ministers on the effectiveness of their Strategies. Guidance on the format and content of such Strategies is expected to be issued to NHS Boards in Spring 2005.

These general legislative and policy messages were further emphasised in the 2003 White Paper for health, Partnership for Care.

“Many people who come into contact with the (health) service already rely on care given by an informal carer. These carers are crucially important to the person they look after but they can still find themselves marginalised by health service professionals. The vital role of carers as major care providers must be recognised at all levels in the NHS and staff must work closely with carers as partners in providing care” (Scottish Executive Health Department, 2003)

### **The impact of caring and the future**

The demographic trend of a declining and ageing population has particular implications for society, government, statutory agencies, unpaid carers and for people needing care. Currently 1 in 8 adults in Scotland are carers (600,000 carers currently estimated), many carers are themselves over 65 and 1 in 5 of carers will care for more than 50 hours a week. It is estimated that by 2037 the number of carers in Scotland will have increased to around 1 million – 1 in 6 of the population (Carers UK, 2001).

Along with this increase in the overall volume of unpaid care, a trend towards an intensification of caring relationships has been identified with a higher proportion of carers having sole responsibility for the person they look after and an increase in the proportion of carers providing the more demanding forms of care (Hirst, 2003). There is also evidence that an increasing proportion of unpaid care is being provided by relatively close family members – adult children or, especially, partners (Hirst, 2001; Pickard, 2002). These trends may well be leading to a greater likelihood of stress and ill-health among carers (Hirst, 2003). A recent analysis showed that people providing high levels of care are twice as likely to be in poor health as non-carers (Carers UK, 2004)

It has been pointed out that as the population ages and there is an increase in the incidence and prevalence of chronic conditions there is a need for a shift in the basic paradigm of healthcare from the isolated episode of treatment to ‘care based on the continuous healing relationship’. (Institute of Medicine, 2001)

A health service which is increasingly oriented towards the establishment of continuous relationships with patients aimed at the management of long term conditions will be one in which continuous and collaborative relationships with carers will be an essential element.

As various methods and levels of care and case management are progressively adopted as part of the move towards a more preventative and proactive model for dealing with long term conditions, carers will play an increasingly important role as partners in these initiatives. Conversely these developments are likely to be of great benefit to carers to the extent that they reduce fragmentation and duplication in the provision of care.

As pointed out in a recent Australian report

“Care co-ordination and case management, often viewed as primarily a service to care recipients, carries direct benefits for carers, particularly carers of people with impaired decision-making capability. Primary carers have been likened to ‘bridges’, connecting their care recipients to health and community care networks. Case management .... can relieve carers from the time consuming detail of investigating alternative services etc .... Case management is a necessary rather than optional form of support for the ‘bridging role’ of primary carers ....”  
(Australian Institute of Health and Welfare, 2004)

## **Scoping the future**

As we move increasingly towards a more collaborative and person-centred approach to health and social care the already critical contribution made by unpaid carers will have an even greater importance. In recognition of this, the Scottish Executive’s Care 21 Change and Innovation Unit has commissioned a comprehensive futures planning exercise on unpaid care. The project will define the role of unpaid care within the changing landscape that Scotland as a society is expected to face over the period 2004-2014. The project is looking at the needs of current and future generations of carers, within a health and social care system in which people will

continue to live longer, will have increased expectations, will benefit from medical and technological advances and in which economic and workforce related issues will pose continual challenges.

Recommendations from the futures exercise will be reported to Ministers in July 2005. It is anticipated that such recommendations will inform policy that will effect the future delivery of services to carers in both the NHS and Local Authorities.

## **What carers need**

Scottish Executive Guidance on the implementation of the Community Care and Health (Scotland) Act 2002 emphasised that unpaid carers require appropriate resources and support to be able to manage their caring role.

It is widely accepted that the impact of caring for unpaid carers can be equated to the impact on professional medical and care staff. The professional workforce receive regular weekend and holiday breaks, adequate equipment, training, practical and emotional support form an integral part of working conditions. Unpaid carers also require adequate resources and support, albeit in different formats, as their caring role can be equally demanding and often comes on top of other employment and family commitments.

It is documented that carers require the following resources:

- 1) information and advice
- 2) training
- 3) practical and emotional support.

### **1. Information and advice**

Unpaid carers require appropriate information and advice at every level of the caring journey. According to carers' own preferences they prefer information directly from NHS contact points or from 'one-stop shops' such as local Carer Centres, rather than having to piece together information from a wide range of sources and agencies.

The type of information required by carers can be identified as:

**Information on the health and medical condition of the person they care for.** Understanding the gradual impact, symptoms and processes of illness e.g. dementia and Alzheimer's, or for example the causes and patterns of schizophrenia, epilepsy, stroke or kidney dialysis, can enable the unpaid carer to understand and plan appropriate medical or care support. This will lead to the empowerment of carers who can assist in predicting and preventing crisis interventions thus avoiding potentially avoidable admissions to acute services.

**Information on health promotion and healthy living.** There is increasing evidence that the pressures of caring lead to stress and mental ill-health and a neglect of people's health and dietary needs. Protecting the health of unpaid carers is viewed by many carer organisations as a public health issue. Viewing the health of carers in this way will provide long term benefits to the NHS. Healthy carers in the community can be as essential as healthy nurses on every ward. Therefore

information on the advantages of healthy diet, exercise and techniques to combat stress are important to ensure that carers can manage the negative effects of caring.

**Information on the range of support that is available to them.** Although support is available to carers, information on how to access it is not always readily available. Carers require information on finance and benefits for themselves and the person they care for; short breaks and breaks from caring (respite); equipment and adaptations to support daily living; practical and emotional support. Making this information easily accessible provides carers with choice on the services best to suit their needs and prevents the inevitable frustrations associated with navigating the 'system'.

## **2. Training.**

NHS research has shown that systematic training for unpaid carers produces a better quality of life for the carer and person cared for, as well as tangible economic savings from reduced NHS and social care intervention, and prevention of repeated hospital admission. For example, a recent randomised controlled trial looked at the effects of providing unpaid carers of disabled stroke survivors (patient median age 76) with training in basic nursing techniques relating to stroke and hands on training in such areas as lifting and handling and continence issues. Improvements were shown across a range of outcomes for both carers (e.g. quality of life, anxiety and depression scores) and patients (e.g. quality of life, burden of care) (Kalra et al., 2004) An economic evaluation showed significantly reduced costs of care (Patel et al, 2004).

Appropriate training courses on aimed across the spectrum of caring, preferably early in the caring role, can play a significant part in building carer knowledge and confidence and in facilitating peer support.

In line with the concept of the 'expert patient', training for carers can create 'expert carers', who are knowledgeable in medication regimes, early symptom recognition, pain and behavioural management. The 'expert carer' can effectively work alongside the health professional to deliver quality care, and as guided by professional advice can provide peer support to others in similar circumstances.

Training courses for carers funded and promoted by the statutory sector will allow all to participate. Funding for alternative caring arrangements while carers are undertaking training - particularly for those with the heaviest caring responsibilities – will enable carers to participate and provide long term benefits to the NHS.

Training programmes should be designed with the appropriate balance of professional input and peer support, covering topics such as: assessment and pathways to NHS and social care support; use and effects of medication; moving and handling; emotional aspects of caring; healthy living and health promotion. Such courses are important to carers and can help them with their caring responsibilities.

Ideally, carers should have the opportunity to choose from a mixed programme of generic courses, specialist courses and group work programmes (on emotional aspects of caring) to develop the appropriate mix of training support for their specific needs at different stages in the caring journey.

### **3. Practical and emotional support.**

Carers report that they require both emotional and practical support to assist in their caring responsibilities. The practical support needs of carers, particularly of those in intensive caring situations providing 50 hours care and more per week, centre specifically around aids and adaptations, and the provision of regular and planned breaks from caring (respite). The emotional support required takes the form of mentoring, counselling and peer support.

**Practical Support: aids and adaptations.** Appropriate aids and adaptations play a significant part in easing living routines, particularly where provision is part of long-term planning to allow patients and their carers to shape their environment to their long-term needs. Carers report great improvements to their lives and caring roles as a result of often small adaptations and supporting aids

Many NHS Boards and Local Authorities provide extensive aids and adaptation stores. These can be accessed by patients and carers but are not always widely promoted and carers often report a lack of information about their existence.

Increasing carers access to information about aids and adaptation stores, as well as reducing the bureaucratic procedures associated with accessing equipment will enable carers to work alongside professionals in maintaining the patient at home .

**Practical support: rehabilitation, short breaks and breaks from caring.** The provision of short breaks and planned breaks from caring is reported by carers as an essential requirement to help maintain the caring relationship. Although 'respite' is often seen as a social care issue joint planning to increase the capacity of flexible and planned respite services would thus further assist in the caring role.

Clearer strategies for rehabilitation programmes, particularly for people with complex needs, linked to the provision of planned respite opportunities should be explored. There is scope for developing rehabilitation wards within NHS settings with combined input from medical, social care and voluntary sector practitioners to provide holistic and high quality care environments which combine rehabilitation and respite functions for the benefit of the individual and the caring partnership and relationship.

**Emotional support.** For thousands of unpaid family carers the ability to cope with their role as care providers depends on managing the emotional impact of impairment, illness and caring. Impairment and illness often have significant impact on 'natural' relationships between people and their life expectations: frustration, anger, guilt, depression and a sense of hopelessness often result. Planned support for unpaid carers should include the provision of emotional support, counselling, peer group support and mentoring.

As with training programmes on the practical aspects of caring, NHS investment and support of emotional support programmes and facilities would provide a significant 'resource' to keep carers well supported to cope positively with their caring role

## **What the NHS can do to support carers**

The previous section has outlined the kinds of support and training which carers need from the NHS. The following proposals outline steps which the NHS can take to deliver this agenda.

**1. Make carers' health a public health issue.** With increasing evidence of the detrimental impact of caring on the emotional and physical health of unpaid carers, carer organisations maintain that government and NHS should regard the health of unpaid carers as a public health issue. Preventative action, healthy living advice and health promotion for carers will produce health and quality of life benefits for carers and the person cared for.

Practical examples include NHS Lothian's inclusion of carers of all ages in free flu inoculation programmes (previously only supplied to people over the age of 65), or Edinburgh Leisure's pilot programme of issuing free and reduced leisure access cards to carers via carer organisations to encourage greater access and take up of wide range of public leisure facilities.

**2. NHS Carer Information Strategies.** Full and systematic implementation of local carer information strategies is needed to identify and support carers at the point of patients' entry to the NHS. In this context the systematic implementation of carer registers within new GP contracts would address one of the key gateways for recognition and support identified by unpaid carers and health professionals. To meet the specific cultural and medical needs of minority communities local strategic action plans should explicitly identify future formats and delivery of information to hard-to-reach groups.

**3. Carer participation and partnership involvement in planning.** The continued recognition of carers as key providers rather than users of services is fundamental to their role as strategic partners at all levels of health care. Consideration could be given as to how to strengthen the formal role of carer representation within emerging planning structures thus enabling carers to provide information on what could be developed locally to facilitate hospital discharge and prevent hospital admission.

**4. Carer training.** The previous section outlined the types of training required so that carers can maintain their own health and well-being and maximise their contribution to the health and well being of the person they care for. The NHS should develop a national framework for the development and implementation of the training programmes which are required.

**5. Building 'carer awareness' into professional training.** The 'carer dimension' should be included in the professional training and study programmes of professional staff at all levels. A lead has been taken by the Royal College of Psychiatrists. From 2005 that College will require post graduate accreditation to have a carer awareness component to the curriculum and that this be carer led.

Current draft statutory guidance states that NHS health boards and local authorities must ensure that frontline staff and professionals are trained in carer awareness issues. This should include awareness raising about issues relating to young carers. Training should be provided in a range of ways including induction, joint training and on-going education and communication in relation to health and social care.

## **Volunteering**

### **Context.**

2005 is the Year of the Volunteer. The unique contribution of volunteers to health care is being increasingly recognised and encouraged. Not only can volunteers make a valuable contribution to making health care a more human and caring process but the health and psychological benefits to the volunteers themselves are becoming ever more apparent. The range of contributions made by volunteers in health care is vast: from highly generic services such as driving or running shops and tearooms to roles which involve an irreplaceable level of empathy and expertise such as mentors in patient-led self-management programmes.

2004 saw the adoption of a Volunteering Strategy by the Scottish Executive containing the following general definition:

“Volunteering is the giving of time and energy through a third party, which can bring measurable benefits to the volunteer, individual beneficiaries, groups and organisations, communities, environment and society at large. It is a choice undertaken of one’s own free will, and is not motivated primarily for financial gain or for a wage or salary”

The strategy emphasises four key strands:

- Ensure young people are involved in volunteering
- Dismantle the barriers to ensure participation by hard to reach groups
- Improve the volunteering experience
- Have mechanisms in place for monitoring, evaluation and ongoing policy development

and is aimed at embedding and expanding the culture of volunteering in Scotland.

### **Volunteering activity in health care**

In healthcare this policy drive is able to build on a long established tradition of volunteering in the NHS where significant numbers of individuals contribute their time in a variety of settings - hospitals, hospices, health centres and community and local projects. Many volunteers provide “direct” assistance to the NHS and link with a Voluntary Services Managers or another member of staff. Others volunteer with

voluntary organisations – Friends Associations, large organisations like WRVS or Red Cross, or with self help or condition specific groups.

A recent informal survey in Ayrshire and Arran Health Board suggested that almost 1300 volunteers were involved in work in hospital locations. A high proportion of these volunteers were women in the 60 to 75 year old age group.

## **Volunteering in Health is ..**

### **Good for Volunteers**

#### *Volunteering:*

- offers a sense of purpose
- is a chance to give something back
- can be good for your health
- provides social contacts
- offers the chance to gain experience
- can be a way out of dependency

### **Good for Patients**

#### *Volunteers:*

- offer friendship
- can give more time than hard-pressed staff
- do things other people cannot manage
- are often 'people like me'
- may have experience of the same conditions – so understand 'what it's like'

### **Good for Health Services**

#### *Volunteering:*

- forges strong links with the community
- frees up scarce professional resources
- breaks down institutional barriers
- creates an informed and involved public

### **Good for Society**

#### We all benefit if more people:

- get involved in the community
- take responsibility for each other
- understand the importance of healthy lifestyles
- have a stake in improving public services

From *Volunteering in Health*, Volunteer Development Scotland

[www.vds.org.uk/volunteeringinhealth](http://www.vds.org.uk/volunteeringinhealth)

There is increasing evidence that volunteers are being engaged in new ways in the NHS as a result of service redesign, clinical need and agendas such as Fair for All. For example, the increased involvement of volunteers around meal times is partly a

response to concern about nutrition and the development of Standards for Food, Fluid and Nutritional Care.

### ***Acute hospitals.***

In acute hospitals direct volunteers have traditionally been involved in social activities – visiting, reading aloud, arranging flowers - on the wards, in chaplaincy, welcome services, transport and hospital radio. While cafes, trolleys and tearooms are associated with volunteers they are usually run by separately constituted voluntary organisations. There is also evidence that volunteers are being asked to adopt new roles. These include participation as OT/physiotherapy helpers, peer mentors, complementary therapists and involvement in A & E, patient waiting areas, renal services, outpatients and stroke services.

### ***Community and long stay hospitals and hospices***

Volunteers are well established in community and long stay hospitals and hospices. In hospitals, they tend to be concentrated in care for the elderly, assessment and rehab wards and in long stay mental health facilities. Apart from social contact, and befriending, other volunteer services include arts and crafts, gardening, transport, entertainment and information giving. In hospices and palliative care wards, volunteers provide an essential transport service and are found, in considerable numbers, throughout day services.

New developments include increased involvement of volunteers around meal times, the expansion of complementary therapy services in hospices and palliative care and 1:1 befriending - as volunteers follow patients from hospital or hospices into the community.

### ***Primary care, community and local projects***

Volunteers are involved in many community projects, self help and condition specific services provided by voluntary organisations, often on a contractual basis. The majority of Healthy Living Centres involve volunteers in their core health improvement and health awareness activities.

Within the NHS itself there are examples of volunteer involvement in mentoring and befriending projects as well as prescription delivery, information giving, driving and health promotion – all predominately based in health centres and GP practices.

A recent example has been support for breast feeding such as the Glasgow Breast Feeding Initiative. In this project, women who have breastfed for at least three months are offered training by health visitors in order to become a volunteer breastfeeding helper. The volunteer helpers then visit new mothers in the maternity hospital and at home to supplement the care given by healthcare professionals. They are available to provide follow-up support and advice about specific problems. As pointed out by a health visitor involved in the Initiative “Volunteers are an essential part of the Initiative ..... they are asked very different questions by mothers” .

## **Volunteers and self management of long-term conditions.**

As was outlined in the section on self care and self management, volunteers are increasingly involved as mentors and trainers in lay-led self management programmes. There is growing recognition that volunteer peer mentors complement and enhance the service provided by health care professionals. Peer mentors can provide a unique level of empathy, expertise and insight into the realities of the best ways of coping with and managing long term conditions.

As the involvement of volunteers in specific initiatives such as Braveheart and Challenging Arthritis becomes more widespread there is a strong case to be made for 'mainstreaming' the involvement of volunteers by including this as an option in the development of individual care plans. This could have particular relevance in the context of planning services for the elderly.

## **The benefits of volunteering.**

Volunteering is most obviously the source of benefit to those for whom volunteer services are provided. However it is now generally accepted that volunteering has positive effects on the health and mental well-being of the volunteers themselves.

In his study of changing levels of social capital in the United States, Robert Putnam presents a wide range of evidence documenting the powerful effects which the level of social involvement of an individual has on their health (Putnam, 2000). Levels of social connectedness and social involvement are strong predictors of health and psychological well-being. Growing evidence of the beneficial effects of volunteering is one part of this overall picture.

Evidence from Scotland and elsewhere in the UK points to a wide range of positive outcomes related to volunteering. A study by the Institute for Volunteering Research showed positive effects of volunteering among a sample of people with mental health problems (Institute for Volunteering Research, 2003). A recent study in Scotland looked in particular at the effects of volunteering on older people. It found a range of health benefits; psychological benefits such as confidence building and a restoration of a sense of purpose and a sense of achievement; social benefits involving creating new networks and lessening social isolation. (Community Service Volunteers, 2004)

## **The voluntary and community sector**

The voluntary and community sector in Scotland makes a major and growing contribution to the healthcare system. The sector is active in all spheres of health improvement, patient care and patient and public involvement. Thousands of community groups are involved in the health improvement and tackling health inequalities agenda with, for example, more than 100 groups involved in the Have-a-Heart Paisley initiative.

Voluntary organisations play a particularly important role in the context of long-term conditions. Patient groups focused on a particular condition or group of conditions, such as Diabetes Scotland, Asthma Scotland, Cancer Bacup and Alzheimer's Scotland, are major resources in supporting self care and self management.

Voluntary organisations are also often especially valuable in working with groups the NHS finds hard to reach, such as minority ethnic groups, lesbian/gay/transgender groups, refugees and asylum seekers, homeless people, travellers and gypsies, as well those in isolated and rural locations. They help make services accessible and acceptable.

Voluntary organisations nationally and locally are usually supported by a mixture of paid staff and volunteers. Many smaller voluntary organisations could not exist without the support of volunteers, but some of the larger organisations will use only paid staff. Community-based groups are generally active at community or neighbourhood level. They work developmentally and frequently depend upon volunteers and community activists.

The sector consists of a wide range of organisations and groups with varying capacities and abilities, many different visions and a range of internal structures. The challenge for the NHS is to engage in productive partnerships with this diverse and multi-faceted set of groups and organisations.

The statutory and policy framework in Scotland is increasingly emphasising the potential of the voluntary and community sector as a partner of the NHS in delivering health care. In general terms, this builds on the Scottish Compact between the Scottish Executive, its agencies, the NHS and the voluntary sector.

**As part of the Patient Focus and Public Involvement Agenda, NHS Boards throughout Scotland are encouraged to bring a renewed focus to their relationship with the voluntary sector and recognise the valuable contribution it can and does make to health care in Scotland. Local compacts are emerging as an important vehicle for developing the relationship between the NHS and the voluntary sector.**

**Full and equal partnership with the voluntary sector is an inbuilt element of the development of Community Health Partnerships (CHPs). The voluntary sector presence in CHPs will encompass a range of roles including service provision, patient advocacy and involvement in service planning.**

## **Barriers.**

Implementing the kinds of changes implied by the foregoing will not necessarily be easy. In particular a greater emphasis on self care may be seen as cutting against the grain of deeply ingrained models of how health care should be delivered.

A recent editorial in the BMJ pointed towards evidence from a recent survey that primary health care in the NHS is still delivered in a more paternalistic fashion than in other systems. In comparison with Australia, Canada, New Zealand and the United States, 'the United Kingdom performed worse than the other countries in relation of information about medicines, shared decision-making, patients' access to records, preventive advice and self management of chronic disease' (Coulter and Rozansky, 2004). Looking to the future, the authors see little in the new GP contract to encourage patient engagement, seeing it rather as promoting an essentially doctor led model with few incentives for clinicians to empower patients to take control of their own health.

More generally, the traditional bio-medical model of healthcare, to the extent that it shapes medical education and the professional culture of health care delivery will act as a major impediment to developing a greater level of involvement of patients and carers. A broader biopsychosocial model of health will be more congruent with a health service which has transformed its relationships with patients and carers.

It has also been pointed out that a greater emphasis on self care may well serve to further disadvantage those groups who are already disadvantaged in terms of access to health care. Marginalised groups such as people with learning disabilities or cognitive impairment, minority ethnic groups, older people and people living in material disadvantage may be further marginalised because of unequal access to information, help, support and resources. The way to overcome this risk will be to ensure that developments to enhance and support self care and self-management are undertaken with the full involvement of these groups and designed in such a way as to increase their ability to participate.

Many long-term illnesses are disproportionately represented in the more materially deprived social groups and there is continuing evidence that the inverse care law is in operation whereby those who most need health care are least likely to receive it.

Any approach which adopts the development of self care and self management as a major component of the overall strategy to deal with long term conditions will have to address these concerns. The strategy will need to be tailored in such a way that deprived groups are targeted with appropriate methods for involving them. It may be that more intensive methods of providing support for self management may need to be disproportionately provided in deprived areas to counteract the greater ability of more affluent groups to take advantage of new opportunities for self care and self management. This will mean recognising that extra resource may be needed to mean that current inequalities do not lead to future inequities.

## Conclusion.

The need for a 'paradigm shift' in how health care is delivered has been a key feature of the work of the National Framework. Figure 2 shows the main dimensions of this paradigm shift.

As has been consistently emphasized, the main driver of this shift has been the need to reshape a health service designed in the days when the main challenge was acute conditions into a health service geared to deal better with chronic or long term conditions. Episodic care based on the one-off contact between the patient and the

Figure 2                      **THE CHANGING PARADIGM**

<b><u>Old Paradigm</u></b>	<b><u>New Paradigm</u></b>
Geared towards acute conditions	Geared towards long-term conditions
Episodic Care	Continuous Care
Hospital centred	Locally responsive
Patient as passive recipient	Patient as co-provider
Patients as dependents	Patients as empowered
Self care tolerated	Self care encouraged and facilitated
Carers undervalued	Carers supported as partners
Disjointed care	Integrated care
Separate episodes of care	Co-ordinated care
Doctor/patient structured	Team based
Reactive care	Preventative care
Crisis management	Case/care management

health care professional will be replaced as the main form of care transaction with continuous care of long term conditions based on careful monitoring and preventative interventions.

As far as possible the continuous and preventative orientation of care delivered in the community as close to patient as possible will serve to shift the balance away from care delivered in the hospital. Hospital care will be there when needed but only when truly needed and as not as a default option.

A shift in the relationship between patients and health care professionals will be a major component of how health care is reconfigured. As far as is practicable the patient will be regarded as a co-provider of care rather than as a passive recipient of care. Priority will be given to developing the best ways of ensuring the patient is given the skills and the confidence to fulfil this role. Use of the whole range of educational, information and communication resources will be needed – ranging from general health information on the internet to intensive one-on-one training, from handbooks to lay-led self-management courses. Self care will change from being at best tolerated to being recognised as a key component in ensuring the best outcomes of care.

The same drivers which call for a transformation in the role of the patient in optimising care are relevant to the role of the carer. Carers tend to be undervalued with a lack of recognition of their role as vital partners. Caring is often a stressful role and can be damaging to carers health. Carers need support and respite to maintain their own psychological and physical well-being. They need general and specific information and training in order to carry out their caring role in a way that this is best, least stressful and most satisfying for themselves and most beneficial to the person being cared for. This information and training should be provided using the full range of communication media and educational methods.

Long term conditions provide a context in which volunteers – whether in roles specifically related to self-management such as volunteer mentors or in more generally supporting and caring roles – can play a particularly important role.

An element of the shift in health care required to deal with long term conditions is a shift towards less fragmented and more integrated and co-ordinated care. This does not just mean better co-ordination and integration of the work of different parts of the health service but better co-ordination and integration with patients, carers and volunteers. As the emphasis shifts from a dyadic doctor-patient relationship to multi-disciplinary team-based working – patients, carers and volunteers must become members of that team.

## **Recommendations.**

The Scottish Executive should establish a national group, including patients, carers, the voluntary sector and health professionals to develop a supported approach to self-management and should fund and develop a Scottish long-term conditions alliance, to articulate patients' views.

The Scottish Executive should work with NHS Boards to pilot self-management approaches supported by information technology.

The NHS should:

- Make carers' health a public health issue
- Implement fully NHS carer information strategies
- Encourage carer participation and partnership involvement in planning
- Develop and provide carer training
- Building 'carer awareness' into professional training

NHS Boards should develop proposals to promote volunteering in health in accordance with the principles of the Scottish Executive Volunteering Strategy.

As part of the Patient Focus and Public Involvement Agenda, NHS Boards should bring renewed focus to their relationship with the voluntary sector. Local compacts should be developed as an important vehicle for the relationship between the NHS and the voluntary sector. Full and equal partnership with the voluntary sector will be an inbuilt element of the development of Community Health Partnerships.

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