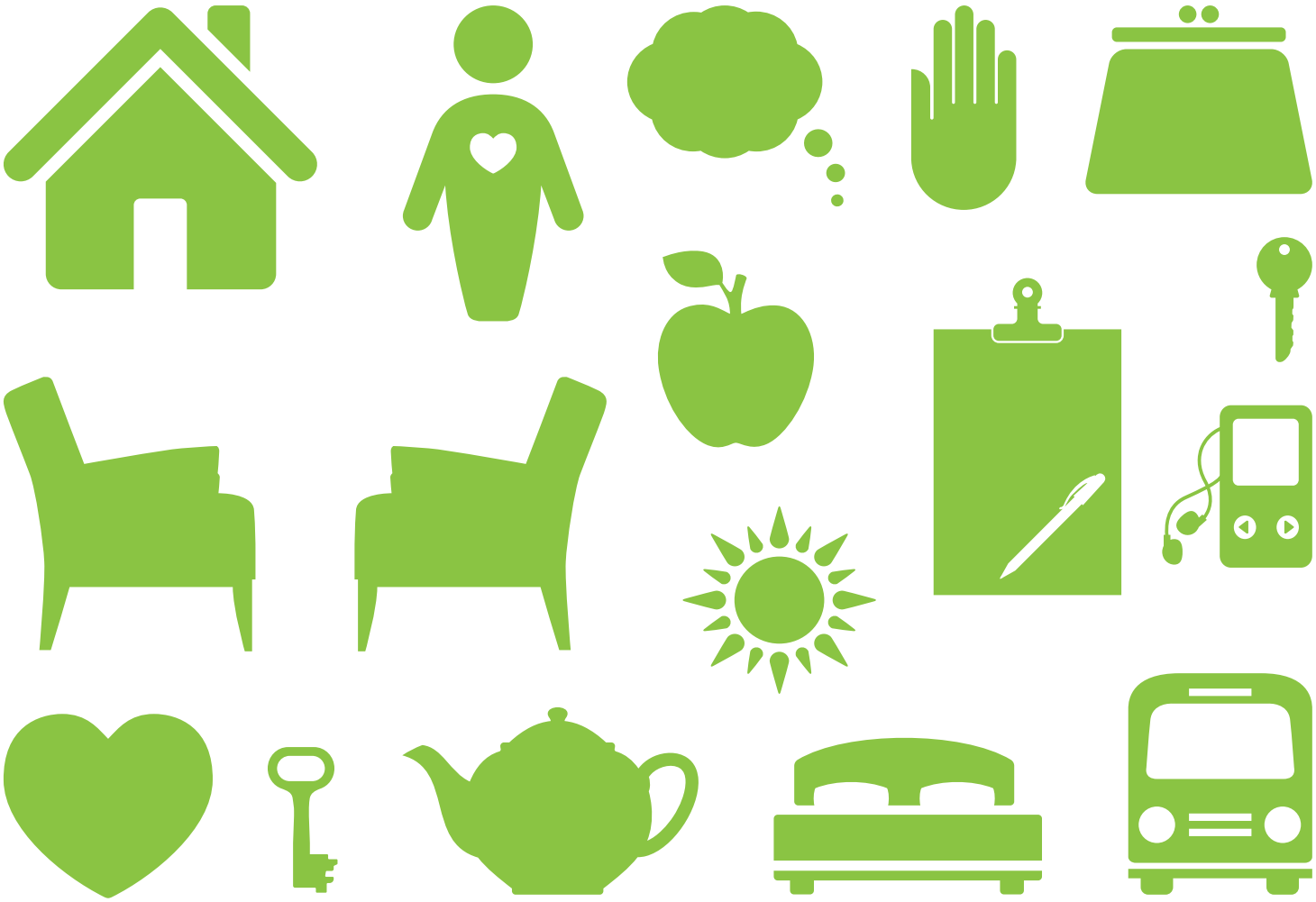

Improving later life.

Services for older people – what works.

We are Age UK

Age UK works to improve later life for the 14 million older people in the UK. We do this by addressing health inequality, reducing loneliness and isolation, improving retirement incomes and tackling poverty and discrimination against those in later life in all its forms. We also speak for the long-term interests of every one of us, so that experiences of ageing grow better for each passing generation.

Improving later life.
Services for older people – what works.

Acknowledgements:

We wish to thank Professor Martin Knapp from the National Institute of Health Research's School for Social Care Research, and Professor Alan Walker from the New Dynamics of Ageing, for help identifying authors and research for this book.

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Project Manager: Dr Susan Davidson

Editorial Board: Phil Rossall and Professor James Goodwin

Caroline Abrahams
Charity Director General, Age UK

Welcome

As a major provider of services to older people, Age UK is deeply interested in what research tells us is known to work. To help inform this debate we've asked experts to write jargon-free summaries of research in their areas.

We think some major themes have emerged that are necessary for effective services for older people. These key messages are not necessarily new but the lessons learned from research have not been consistently followed through into service design and delivery so they therefore bear repeating.

Key messages

One

Service design and delivery should be based on what older people say they want and need.

Two

Carers play a vital to the success and sustainability of interventions.

Three

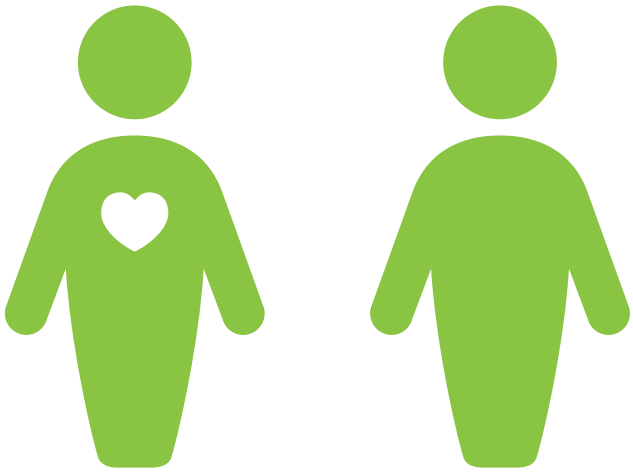
There should be thorough and regular assessments of the needs of both older service users and their carers.

Four

Service design should incorporate from the start a robust evaluation system and a broad and long-term view of likely costs, cost savings and sustainability.

Five

Benefits for older people and carers are likely to go beyond the narrow focus of a particular service. Service providers should value – and make use of – opportunities for additional benefits.



Six

Completion of tasks should not be the only criterion by which a service is judged. Social interaction is often valued as highly by older people.

Seven

Some services which are suited to all potential users, but thought should be given to suitability for groups such as older men.

We would like to thank the National Institute of Health Research's School for Social Care Research and the New Dynamics of Ageing for their help in identifying authors and research. for this book.

Caroline Abrahams
Charity Director General, Age UK

***Geoffrey Filkin** has worked on public service improvement as a senior manager, policy maker, government minister and member of the Lords. He proposed and chaired a House of Lords Select Committee whose report, Ready for Ageing, was published in March 2013. He now chairs the Centre for Ageing Better.*

Foreword

The Lord Filkin, CBE

My granddaughter, if all goes well, will live to be 100; she has the energy to do so! Many of us will live ten years longer than expected at our birth. This increase in our lives is the greatest achievement of our society and offers the potential to *live more, learn more, give more and love more*, as was said to me the other day.

The key question is how to make these years as healthy, happy and meaningful as possible and improve the quality of later life whenever we can.

This sounds a heroic, even utopian, ambition but this excellent Age UK publication makes crucial points about how to realise this vision.

It tells us that service designers and providers should listen to what older people say they want and value, and co-design services with them, rather than doing things to them. We should also need to recognise the huge diversity among older people, and make the best use of the evidence of what works best.

I have recently been appointed Chair of the *Centre for Ageing Better*, to be endowed by the Big Lottery Fund as an independent *What Works Centre*, with a role to synthesise evidence of what older people want, and what works for them. As we build the Centre next year we aim to embed older people's views and values in our work, and to work in partnership with colleagues and friends in the voluntary and charitable sectors, to help maximise the value of the excellent work already taking place there.

***Sandie Keene** is Director of Adult Social Services for Leeds City Council and this year's President of Association of Directors of Adult Social Services. The themes of her presidential year include integration, leadership and unlocking barriers to gaining access to good quality care.*

Introduction

Sandie Keene, President, Association of Directors of Adult Social Services

The Association of Directors of Adult Social Services is the national 'voice' of Directors of Adult Social Services in England. This year, it is my privilege to serve as the organisation's President and so far this has meant involvement at a national level in the widest possible range of issues that affect care and support for our older, disabled or disadvantaged citizens.

If ADASS is to be effective in influencing national policy in order to achieve improving outcomes for the people we support, then reliable and accessible evidence of what works and what doesn't is vital if we are to give out clear messages and lay down principles.

Age UK has identified a need for a summary of baseline evidence showing what is proven to be effective in improving the lives of older people. It is greatly to the organisation's credit that they are working to fill the perceived gap with this publication. I am delighted to lend my support to the project.

The authors in this volume are leading researchers in the field and lend their considerable authority to the issues addressed within these pages. Their contributions are valuable equally for presenting what is evidenced to be successful practice as well as for highlighting what is not. Gaps in our evidence base are highlighted for much-needed future research.

I am pleased to commend this Age UK publication and web materials as a valuable and accessible guide to current best practice in the care and support of older people.

Contents

Part 1
Overarching matters

Part 2
Addressing needs

Service cost-effectiveness: Is it worth it?

***Martin Knapp**, PhD, is Director of the Personal Social Services Research Unit and the School for Social Care Research, London School of Economics and Political Science, where he is Professor of Social Policy.*

Key messages

An economic analysis must take into consideration the context in which it is conducted, including older people's needs, assets, and preferences.

Analyses also need to consider the many different services and systems (e.g. health and social) involved, ensuring that economic pay-offs or burdens are shared out appropriately.

The costs of interventions must be considered alongside intended outcomes, such as better health, improved personal functioning, greater and more meaningful social participation, and enhanced quality of life.

Often, better outcomes come with higher costs; sometimes it is worthwhile to choose an option even though it is not going to generate cost savings.

Money is tight, budgets squeezed, GP appointments hard to get, outpatient waiting lists long, skilled staff over-stretched, eligibility criteria restrictive... and that was *before* the recession.

It seems to have taken a global macroeconomic shock to wake some people up to the fact that resources are scarce. Yet this is the perennial state of the world, of course. There are *never* enough resources to meet everyone's needs or to satisfy everyone's wants, and those who control the

resources have to make tough choices about how to allocate them. This not only affects government ministers, NHS and local authority commissioners, and public sector and other providers, but also personal budget holders – indeed, any individual juggling their own finances.

Each of these decision-makers wants to use their available resources to achieve the best outcomes, perhaps gauged in terms of how well they meet needs, improve social inclusion, health or quality of life, or satisfy preferences. They also need to factor in other considerations, such as protecting the dignity of people using services, or ensuring fair access to support across all parts of a community.

Economics

The pervasive challenge of scarcity is the entry point for economics. One aim of economic analysis is to provide decision-makers with reliable information on how to achieve cost-effectiveness. This information could be needed for a range of 'interventions', a term I use here to refer to a service, treatment, preventive strategy or wider policy framework. In carrying out a cost-effectiveness analysis, an economist would tot up the costs of the intervention (plus the wider package of care and support wrapped around it), subtract any savings that might be generated downstream (for example, because people use fewer services or because admission to a care home is delayed), and then set those monetary figures alongside evidence on the outcomes achieved. The costs and outcomes of the intervention would need to be compared with what would otherwise be done: for example, one service compared with another, or a proposed new policy compared to today's arrangements.

I will come back to how the cost and outcome evidence might be used in a moment. But it is important to emphasise that an economic analysis must be embedded within and informed by the context in which it is conducted. Thus, analysis of services to meet the needs of older people should be aware of people's assets (psychological, social, economic) and preferences. It should understand what the services are aiming to achieve (in terms of outcomes or access, for example), as well as the availability of family or community support, and the broader policy environment.

...those who control the resources have to make tough choices about how to allocate them.

Understanding costs

Older people with long-term care or health needs may require support or skilled treatment from a number of systems – such as health, social care, and housing – as well as unpaid support from family or friends. This in turn makes it necessary to tackle the perennial issue of coordination across agencies – and coordination of budgets – to ensure, first, that different entities work together to (say) deliver the right services, and second, that the economic pay-offs or burdens are shared out appropriately. Often, action by one service or system has its greatest impact elsewhere, which could be a disincentive to act, especially when budgets are under pressure. In fact, many things get in the way of good coordination, including professional rivalry, narrowly framed performance indicators and the slow churn of bureaucracy.

Achieving outcomes

The aim of care and support for older people is *not* to save money, or at least one hopes not, but to save and improve lives. The cost of an intervention, or better still the relative costs of two or more interventions, must therefore be considered alongside information on the relative outcomes, such as better health, improved personal functioning, greater and more meaningful social participation, and enhanced quality of life.

Cost-effectiveness

A cost-effectiveness analysis therefore does exactly what it says: it looks at *both* costs *and* outcomes. If one intervention is simultaneously less costly and more effective than its comparator, then it would probably look attractive to the hard-pressed budget-holder: it improves health or wellbeing while also saving money, so what is not to like? In circumstances like these, the implications of a cost-effectiveness study are generally easy to tease out. This does not mean that the lower-cost, better-outcome option *always* gets chosen, for other considerations (such as fairness) might trump cost-effectiveness, but at least the economic argument is clear.

Complications arise when one intervention achieves better outcomes than the other, but only at *higher* cost. The decision-maker faces a quandary: are the better health, wellbeing or other outcomes *worth* the greater expenditure needed to achieve them? There is no simple, scientific or objective way to judge 'worth' in these circumstances: it is a value judgement. Someone has to look at the trade-off between better outcome and higher costs, and then choose the best course of action. Politicians are elected to face up to quandaries of this kind. Similarly, health and social care commissioners are employed to weigh up complex evidence and take decisions. In fact, each and every one of us makes this kind of value judgement in our personal and family lives: the alternative which pleases us most or which has the best outcomes might well be more expensive than the alternatives, but we still might choose it because we think it is 'worth it'.

Is it worth it?

One intervention could therefore be cost-effective even when it is more costly than the alternative(s) with which it is compared. NICE – the National Institute for Health and Care Excellence – has a framework to help the groups developing its clinical and public health guidelines to decide whether better outcomes are 'worth it'. Their approach uses a generic measure of health outcome – the quality-adjusted life year (QALY) – that can be applied across most diagnostic areas. It also uses a recommended threshold value: a medication or appliance that costs more than £20,000 per QALY might not be considered 'worth' it – the money could perhaps be better spent somewhere else in the NHS. In social care, we do not yet have a similar approach, although it is certainly under discussion.

The NICE threshold is only there to provide guidance; it is not a hard and fast rule. But what it does so well is to emphasise to everyone – to doctors and nurses, patients and carers, taxpayers and voters – at least three important things: (a) resources are scarce; (b) tough choices have to made about how to deploy them; and (c) sometimes it is worthwhile to choose an option even though it is not going to generate cost savings.

Martin Knapp (2013) Prevention: wrestling with new economic realities. *Tizard Learning Disability Review*, Volume 18 [this is only published online at the moment but will be in the paper version very soon, in Issue 4 of this year.]

Martin Knapp, Annette Bauer, Margaret Perkins, Tom Snell (2013) Building community capital in social care: is there an economic case? *Community Development Journal*, 48, 313–331.

Martin Knapp (2013) Making an economic case for better mental health services, in Graham Thornicroft et al et al (Editors) *Improving Mental Health care: The Global Challenge*, Wiley.

Someone has to look at the trade-off between better outcome and higher costs, and then choose the best course of action.

What works in partnership working? Integrating health and social care.

***Jon Glasby**, BA, MA/DipSW, PhD, PG Dip (HE), is Professor of Health and Social Care and Director of the Health Services Management Centre, University of Birmingham.*

Key messages

The division between health and social care services is becoming increasingly unfit for purpose.

Simply changing structures has not worked in the past.

Research suggests that some fruitful approaches for integrating health and social care could include:

- aligning work cultures of front-line staff;
- enabling personal budget-holders to join up services from the ground-up
- being clear about outcomes, so that integration is only ever a means to an end.

When frail older people need practical help or develop a crisis in their health, they can often find themselves caught in the 'no man's land' between health and social care. Sadly, it's not uncommon for one agency to say that the person is the responsibility of another organisation (and *vice versa*), so that our effort goes into handling boundary disputes rather than providing high quality care to people in need.

Unfortunately, much of this is designed into our current structures and is very difficult to overcome. Since the creation of the welfare state, we've had a system which assumes it's possible (and even meaningful) to distinguish between people who are 'sick' (who we see as having 'health' needs met free at the point of delivery by the NHS) and people who are merely 'frail or disabled' (who we see as having social care needs met by local Councils and

subject to means-testing and charging). Arising out of this are a series of practical divisions, with different budgets, different geographical boundaries, different legal frameworks, different ways of training staff, different IT systems and different approaches to charging for services.

Whether or not this distinction ever made sense, it feels increasingly unfit for purpose given major demographic changes – **and ever since we've been learning the hard way that people don't live their lives according to the categories we create in our welfare services**. Real life is always much more messy than this, and most older people say they don't care who meets their needs as long as they are met. Thus, the task is to find a way of joining up all this complexity behind the scenes so that older people get the co-ordinated, person-centred care they need and deserve.

Of course, doing this in practice is inherently difficult. Different governments have been trying to find a way forward since at least the 1960s and, if it was easy, we'd have cracked it by now. Under New Labour, policy makers developed a range of approaches to bringing down what they described as a 'Berlin Wall' between health and social care, while the Coalition has talked repeatedly about its desire to create more 'integrated care'. However, actually delivering this in a system not designed with integration in mind remains challenging. As one commentator[1] has put it: 'you can't integrate a square peg into a round hole.'

Moving forwards, the current economic context makes joint working even more important – but also more difficult. With very tight finances we will have to find new ways of working together to make best use scarce public resources. However, financial pressures could also encourage different health and social care organisations to retreat back into their previous organisational and professional identity, to focus only on core business and to try to pass costs off on their 'partners'. In everyday life it's well known that money worries can damage the best of relationships – and the same could be true here.

As everyone tries to grapple with these dilemmas, the research suggests that one thing won't work and that another three or four approaches might. What doesn't work is simply trying to change organisational structures[2 3 4 5]. Although this looks dramatic, simply merging organisations and functions can create massive upheaval that makes things worse rather than better (often for two years or more after the initial change). In the NHS in particular our structures change so often that we have typically just got back to where we were before when then the whole thing changes again. Only half in jest has one commentator[6] described the NHS as an "organisational shantytown" where we hastily cobble together our structures and no one bothers to do it too carefully because we know the bulldozers will come again in six months' time and displace us somewhere else.

In contrast, research and experience[7] suggest that more fruitful approaches might include:

- Working with front-line health and social care practitioners to explore their different value bases, cultures and professional contribution. This can sound woolly, but the **main barriers are often cultural and working carefully with front-line staff to develop new, more joined-up approaches is crucial**.
- Exploring the potential of personal budgets to enable older people and other service users to join up their own care and support in a way that makes sense to them. Rather than trying to join things up top-down (by merging budgets, management teams and so on), this is about enabling people to integrate care bottom-up.

With very tight finances we will have to find new ways of working together to make best use scarce public resources.

- Being clear with local services what outcomes older people can expect – but being much more flexible as to how local services can best organise what they do to meet local needs. This involves being clear what success would look like (and how we'd know if we'd achieved it), but recognising that there are no easy answers and that every locality will be very different in terms of its history, culture, geography and relationships. These things matter and there can be no 'one size fits all.'

Going back to New Labour's analogy of the 'Berlin Wall', it took us an awful long time to demolish the Wall once it was up – and in the meantime we had to find ways of making do as best we could, working around and climbing over or tunnelling under where security was at its weakest. You can always take analogies too far – but there may be lessons here for health and social care.

For further information and a summary of the research cited in this article, see:

Glasby, J. and Dickinson, H. (2014) *Partnership working in health and social care* (2nd ed.). Bristol, The Policy Press

This is part of a series of very practical 'how to' books for front-line workers, students, managers and policy makers (the 'Better Partnership Working' series).

Further resources on partnerships, collaboration and integration are also available via http://www.birmingham.ac.uk/schools/social-policy/departments/health-services-management-centre/work/partnerships-collaboration-integration.aspx

[1]Leutz, W. (1999) Five laws for integrating medical and social services: lessons from the United States and the United Kingdom, *The Milbank Quarterly*, 77(1), 77–110

[2]Field, J. and Peck, E. (2003) Mergers and acquisitions in the private sector: what are the lessons for health and social services?, *Social Policy and Administration*, 37(7), 742–755

[3]Fulop, N., Protopsaltis, G., Hutchings, A., King, A., Allen, P., Normand, C. and Walters, R. (2002) Process and impact of mergers of NHS trust: multicentre case study and management cost analysis, *British Medical Journal*, 325, 246–252

[4]Fulop, N., Protopsaltis, G., King, A., Allen, P., Hutchings, A. and Normand, C. (2005) Changing organisations: a study of the context and processes of mergers of health care providers in England, *Social Science and Medicine*, 60(1), 119–130

[5]Edwards, N. (2010) *The triumph of hope over experience: lessons from the history of reorganisation*. London, NHS Confederation

[6]Walshe, K. (2003) Foundation hospitals: a new direction for NHS reform, *Journal of the Royal Society of Medicine*, 96, 106–110

[7]For a summary, see Glasby, J. and Dickinson, H. (2014) *Partnership working in health and social care* (2nd ed.). Bristol, The Policy Press

...the task is to find a way of joining up all this complexity behind the scenes so that older people get the co-ordinated, person-centred care they need and deserve.

The dignity of older service users

Key messages

Dignity is a *personal* concept, involving individual identity and self-respect.

From the perspective of older people, the psycho-social dimensions of care become increasingly important as health declines.

Older people need to be asked what they feel is important for their dignity, and at regular intervals over time.

The dignity of the person providing care is crucially important to the dignity of the older person.

Promoting dignity in care has been a core policy aim for many years, yet is still lacking in many settings. The vagueness of the term can be unhelpful when developing strategies to support older people and understanding its complexity is therefore vitally important.

Dignity is a *personal* concept, involving individual identity and self-respect. The potential for a loss of personal dignity increases with age, especially in the context of declining health. Falls, continence problems and loss of mobility, for example, affect self-respect in profound ways[1 2]. But dignity is also a social concept, involving social and cultural practices, institutional systems and interpersonal behaviour. Personal and social meanings of dignity are strongly entwined – not least in later life in the context of long-term illness and frailty.

Importantly, in both personal and social meanings, dignity is relevant to those who provide care as well as those who receive it. For example, service users regard efficiency and reliability in a service as an indication of respect[3] but these also contribute to the dignity of the care worker, whose self-respect is enhanced when a job is done well[4]. At the same time, if the

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dignity of a care worker is breached the quality of their work and the dignity of the service user are put at risk. This occurs, for example, when home care workers have insufficient time to attend to anything other than older people's basic functional needs[5 6]. Recent evidence has highlighted how an emphasis on the financial sustainability of organisations has come to dominate organisational cultures with adverse effects on relationships between front-line staff and older people[7 8].

Evidence shows consistently that personal dignity is undermined by the loss of independence associated with declining health and that anxiety over the prospect of further deterioration in the future exacerbates this[9 10]. Older people make strenuous efforts in order to minimise the risk of becoming a burden, and maintaining self-reliance can enhance a sense of self-respect. At the same time, older people must also make major adjustments to their changing circumstances and maintain dignity through acceptance of their need for help. How to strike a satisfactory balance between these is a complex and deeply personal matter and the chance to talk things over with trusted family, friends or professionals can make a significant and positive difference. The help of professionals is all the more important when people are bereaved.

The potential for a loss of personal dignity increases with age, especially in the context of declining health.

A range of factors determine individual preferences concerning how support is given, including social and cultural background, migration experience[11] and individual life histories. People's perceptions of how they wish to be supported also change over time, in line with changing circumstances.
From the perspective of older people, the psycho-social dimensions of care become increasingly important as health declines[12], suggesting that attention to social isolation is as important as meeting functional needs. What might appear insignificant to a care provider might be deeply significant to the service user and their family[13 14 15] and personal dignity is affected profoundly by the ways in which members of staff behave towards older people.

Examples given by research participants include appropriate and polite forms of address; acts of courtesy (such as giving people time to say and do things); and an attentive service culture in which older people are listened to and their needs are noticed. The importance to personal dignity of the style of communication between front-line staff and older people should not be underestimated.

The evidence leads to the inevitable conclusion that dignity in services depends on both social and personal meaning of dignity. This requires attention to organisational cultures and conditions of work as well as respect for the individuality and human rights of older people. Practical steps that could be taken include commissioner-led reviews of contracts for health and social care services in order to assess their capacity to promote dignity in its fullest sense as well as related staff development and education.

[1]Lloyd L, Calnan M, Cameron A, Seymour J and Smith R. (2012) 'Identity in the fourth age: perseverance, adaptation and maintaining dignity' *Ageing and Society / FirstView Article / September 2012*, pp 1–19 DOI: 10.1017/S0144686X12000761

[2]Hall S, Longhurst, S and Higginson I. (2009) 'Living and dying with dignity: a qualitative study of the views of older people in nursing homes'. *Age and Ageing* 38: 411–416 C doi: 10.1093/ageing/afp069 reserved.

[3]Lloyd et al 2012 *op cit*

[4]Rodriguez J. (2011) '"It's a Dignity Thing": Nursing Home Care Workers' Use of Emotions.' *Sociological Forum*, 26 (2), 265–286. DOI: 10.1111/j.1573-7861.2011.01240.x

[5]Vaarama M.(2009) 'Care related quality of life in old age'. *European Journal of Ageing* Vol 6:113–125 DOI: 10.1007/s10433-009-0115-y

[6]Calnan M, Tadd W, Calnan S, Hillman A, Read S, Bayer A. (2012) 'I often worry about the older person 1 being in that system': exploring the key influences on the provision of dignified care for older people in acute hospitals? *Ageing and Society* first view DOI: 10.1017/So686X14412000025

[7]Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry HC 947 London: The Stationery Office

[8]Pleschberger S. (2007) 'Dignity and the challenge of dying in nursing homes: the residents' view'. *Age and Ageing* 36: 197–202 doi:10.1093/ageing/afl152

[9]Lloyd et al (2012) *op cit*

[10]Hall et al (2009) *op cit*

[11]Giuntoli, G., Cattan, M. (2012) The experiences and expectations of care and support among older migrants in the UK, European Journal of Social Work, 15(1), pp. 131–147.

[12]Vaarama (2009) *op cit*

[13]Woolhead G, Calnan M, Dieppe P and Tadd W. (2004) 'Dignity in older age: what do older people in the United Kingdom think?' *Age and Ageing* Vol 33 (2): 165–170 3 DOI: 10.1093/ageing/afh045

[14]Lloyd L, Calnan M, Cameron A, Seymour J, Smith R, and White K. (2011) *Maintaining Dignity in Later Life: A longitudinal qualitative study of older people's experiences of support and care. New Dynamics of Ageing Findings Number 8.*

[15]Harnett T. and Jonson H. (2010) '"That's not my Robert!" Identity maintenance and other warrants in family members' claims about mistreatment in old age'. *Ageing and Society* 30 (4): 627 647 DOI: 10.1017S0144686X09990584

Falls, continence problems and loss of mobility, for example, affect self-respect in profound ways[1 2].

Safeguarding

Key messages

Local safeguarding systems need investment, support, monitoring and governance.

Good partnerships in adult safeguarding need fostering at frontline, managerial and leadership levels.

There is scope for managers to ensure that older people are involved in practical prevention and response, as well as quality assurance and governance.

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Adult Safeguarding is the term used in England to refer to systems and practices in place to prevent and respond to the abuse, mistreatment and neglect of vulnerable adults. Since the year 2000, there has been Department of Health and Home Office guidance[1] about local policy and procedures. In the year 2010–11, there were 95,000 adult safeguarding referrals to local authorities in England and the number is growing annually.

The Care Bill 2013 moves adult safeguarding to a statutory basis, with new duties to have a local Safeguarding Adult Board (SAB), and for its member agencies to co-operate. It sets out the remit of Safeguarding Adult Reviews to find out what might have gone wrong and what lessons can be learned from incidents of serious harm or agency failings[2]. This new legislation will be accompanied by further government guidance.

Commissioners and senior managers in statutory and other organisations need to work in partnership at local level to manage the implementation of these sections of the Care Bill (and others of course). While this is a familiar area to local authorities – who have been lead agencies locally since 2000 – in some areas roles and responsibilities need clarifying at SAB level, including financial

commitments. Recent research on the running and governance of Boards[3] provides useful background to the partnerships necessary. Like many research and development studies and resources, this is available on the SCIE[4] website.

At local level, managers and politicians should assure themselves that the systems of adult safeguarding are effective and that outcomes are as good as possible for people who have been harmed or placed at risk. We lack conclusive research about which organisational models lead to better outcomes – whether it is best to have specialist or general teams – but research is investigating this question[5].

Local government has been active in peer audit of its systems and the overviews of such evaluations are shared[6]. They are required to submit national returns of safeguarding data to the Health and Social Care Information Centre (HSCIC), and research is investigating trends of alerts and investigations. Overall, there are many data sources for different aspects of adult safeguarding – ranging from prevalence studies to collections of data about criminal persecutions and complaint data. Many are usefully reported in the Annual Report of each local SAB.

Senior managers and policy makers are now well equipped with data about risk factors, prevalence and different types of abuse[7].

...we all need good human resource (HR) practices, such as checking references and criminal record status.

There is considerable media and public interest in the abuse of vulnerable adults, as the Francis Report[8] into Mid-Staffordshire Hospital illustrates. Research has also focused on financial abuse – including new crimes such as scamming and identity fraud[9]. This highlights the need for good communication with banks and the potential for Trading Standards professionals to assist in tackling 'grooming' and stopping large-scale extortion and crime syndicates who are preying on older people. Older people's groups need to engage with such preventive efforts.

While there is not much definitive data about prevention of abuse and neglect, there are indications of what works. Local managers and commissioners are responsible for aspects of these – such as ensuring that there are whistle-blowing policies in their own organisations and those from whom they commission services. They are responsible for assessing and managing risk – often a difficult balancing act between over- and under-protection. So, for example, we all need good human resource (HR) practices, such as checking references and criminal record status. There is evidence that this helps with prevention. Older people and carers need to have confidence that prevention is proportionate and effective.

Education about how to recognise elder abuse has some positive effects although these may not be long-lasting[10]. Local SABs need to ensure there are robust training programmes, ranging from raising awareness to training about investigations. Less is known about what works best in building up older people's resilience and ability to recover from abusive experiences. The Mental Capacity Act 2005 (MCA) appears to have improved safeguarding professionals' confidence in acting in a person's best interests when the person is not able to make decisions for themselves (e.g. they have severe dementia)[11]. This may include building up evidence for prosecutions. However, knowledge of the MCA is often patchy, particularly among healthcare staff[12].

Theories of elder abuse being the product of family carer stress are largely not supported by research although there is evidence that people who are not able to manage to deliver good care to their family members, e.g. a spouse, may be enmeshed in difficult relationships. Commissioners and managers also need to pay attention to the links between elder abuse and domestic violence. The experiences of domestic violence services in offering sustained 'victim' or 'survivor' support could help abused older people. Service connections between domestic violence and adult safeguarding need to be stronger. There is also emerging research on 'perpetrators' of abuse in hospital and care home settings to help answer the long-standing questions about whether there are 'wicked people' or 'wicked situations'[13]. The answer appears to be 'both' and that both can be challenged.

The repertoire of responses to victims or survivors of elder abuse is limited in its evidence base. **Access to justice has improved, with opportunities for victims' evidence to be collected and presented more sensitively and new crimes on the statute** (e.g. wilful neglect or mistreatment of a person lacking mental capacity). Some small-scale research has pointed to the value of group and individual support and therapy[14], both of which need to be commissioned more widely and evaluated.

The 'social problem' of elder abuse is now widely recognised – to such an extent that it may sometimes be over-estimated and affect older people's willingness to engage with services. In the new era of adult safeguarding, where risks are generally known and systems are in place, the work of managers and commissioners is moving to ensure that outcomes are positive and that prevention is addressed. They will need the support of older people as volunteers, as active citizens, as campaigners and advocates.

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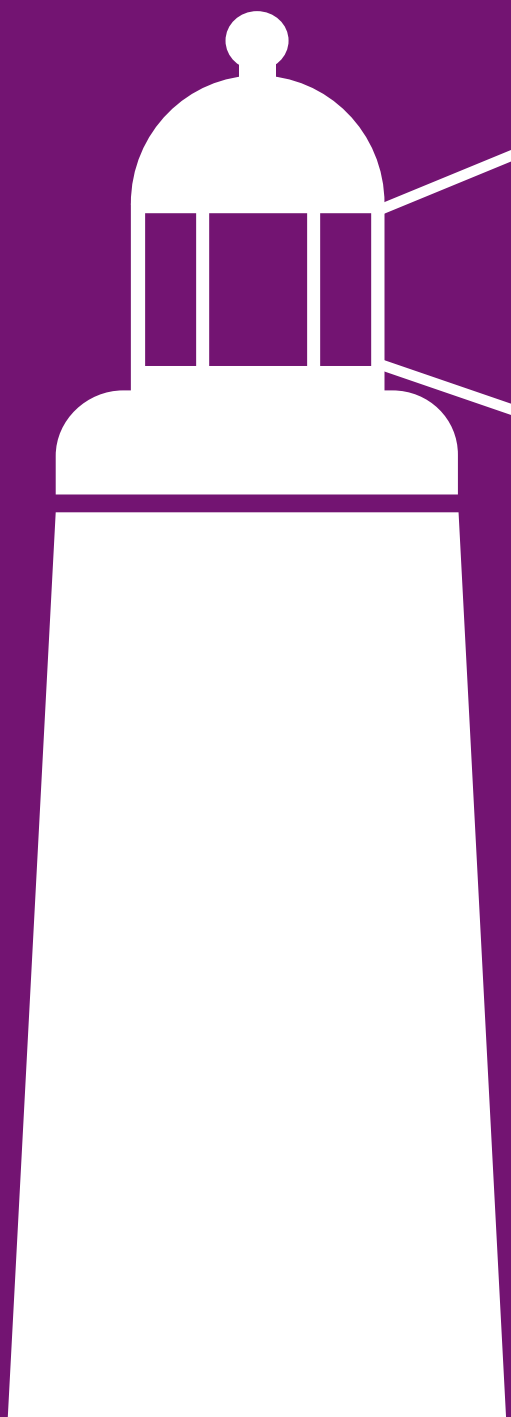

Local safeguarding systems need investment, support, monitoring and governance.

Supporting older people and carers

Caroline Glendinning,
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Key messages

Crucially important, an older person's and any carer's assessments should be co-ordinated; information from both should be brought together in determining the level of personal budgets and planning how they will be used.

Equally important (where both carers and older people want this), carers should be involved in planning how the older person's personal budget is used.

Carers should be offered and encouraged to have a *separate* carer assessment, as it can be difficult for them to discuss their own needs and care-related difficulties in front of the person they are caring for.

Regular reviews of carers' needs should be undertaken; again, these should be co-ordinated with older people's reviews.

Background

Current English social care policy and practice emphasise the importance of older people having choice and control over their own, personalised support arrangements, primarily through the allocation of personal budgets. Relatives and others providing 'regular and substantial' care also have rights to separate assessments of their needs, including needs relating to employment, training and leisure activities; and to support to help them continue caring. But these policies have largely developed separately from each other, despite the interdependence of many older people and the relatives who care for them.

Current Department of Health (2010) guidance recommends that during an older person's assessment any **carers should always be asked whether they are willing and able to continue caring**. Carers should also be offered an assessment in their own right; this should take place at the same time as the older person's assessment and before the latter's personal budget is reduced to take account of help given by the carer. Support planning should be informed by both the older person's and the carer's assessments, so there is an integrated approach.

Outcomes for carers of older people

Research shows that personal budgets for older people can have positive outcomes for carers too. Carers of people with personal budgets are more likely to report feeling in control of their lives and to view their care-giving role positively. Positive outcomes for carers are more likely to arise when personal budgets allow carers to pay other people to do some tasks they have previously undertaken themselves; spend more time with other relatives and friends; or spend more quality time with the older person.

Benefits for carers can also arise indirectly. If carers see older people receiving good quality, appropriate support and experiencing improved quality of life, this can relieve carer anxiety and stress.

…carers should always be asked whether they are willing and able to continue caring.

Practice inconsistencies

Currently, carers' involvement in older people's assessments and in planning how to use personal budgets lacks clarity and consistency. Carers do appear generally to be asked about their willingness and ability to continue caring and about any support they need to continue doing so, but this is usually during the older person's assessment. Moreover, older people's assessment forms are rarely designed to record carers' needs in detail. Some carers report practitioners assuming that they will continue providing care. Few carers take up the offer of separate assessments of their own; where they do, this may be some time after the older person's assessment. This means that detailed information about the carer's own circumstances is neither available nor taken into account in calculating the older person's personal budget or planning their support.

Optimising outcomes for carers

Optimised outcomes for carers are most likely to arise from the following approaches to assessment and support planning for personal budgets:

- In conducting social care assessments of older people, practitioners should not assume that carers are willing and able to continue providing the same amount of help. Nor should carers living separately from an older person be assumed to be under less pressure than those sharing the same household. **Carers should be offered the opportunity to reduce the amount of help they provide, if this is proving stressful or putting their own health at risk**.

- Older people's assessments should include clear prompts to ask carers whether they are willing and able to continue caring, and about any support they need to do so. Assessment forms should include sufficient space for carers' circumstances and any needs to be recorded in detail.

- **Carers should be encouraged to take up the offer of their own, separate assessment**. Carers may not feel comfortable being asked in front of the older person about their care-related difficulties or help they need to continue caring. Separate assessments also provide formal recognition of the caring role, offer carers space to reflect on the psychological and emotional impacts of caring, and provide a critically important opportunity to inform carers about local authority and other sources of information and help specifically for them, including local Carers' Centres. These activities are unlikely to fit comfortably within an older person's assessment. Separate carer assessments are also vital if an older person is resistant to receiving outside help or insists that all her/his needs can be met informally.

- Councils should ensure that all practitioners conducting assessments have up-to-date information about council grants and services for carers and about other local resources such as Carers Centres. Practitioners should be proactive in offering this information, even if carers appear currently not to need it – **carers want professionals to help them plan ahead, rather than wait for a crisis**.

- Regular reviews of carers' needs should be undertaken; these should be linked to routine reviews of the older person. Carers' needs and circumstances may also change independently of the older person's, and such changes can adversely affect their capacity and willingness to care.

- The level a personal budget should not be reduced to take account of help received from a carer until the carer's ability and willingness to continue caring and any related support needs have been fully assessed.

- **Crucially important, an older person's and their carer's assessments should be co-ordinated; information from both should be brought together in planning how a personal budget is to be used**.

- Equally important, carers should be able to play a full role in planning how the older person's personal budget is to be used, especially where some of the older person's budget is earmarked for breaks or respite that can also benefit a carer. Equally, carers will only derive indirect benefits from the older person's personal budget if they are happy about the appropriateness and quality of the older person's care.

- Finally, practitioners need to be sensitive to the wide variety of care-giving relationships; some older people and carers (for example, adult sons and daughters with families of their own) will want to maintain relative independence from each other; others (e.g. elderly spouse carers) will be characterised by high levels of mutual support and interdependence.

The 2013 Care Act will give carers rights to public support on the same footing as the rights of those they support; this is likely to increase pressures for greater clarity over carers' eligibility for support in their own right.

Acknowledgement:

Some of the material in this chapter draws on independent research commissioned by the National Institute for Health Research School for Social Care Research. However, the views expressed are those of the author and do not reflect the views of the NHS, NIHR, or Department of Health.

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Personal budgets can have positive outcomes for carers if carers are involved in planning how the budget is used.

SPOTLIGHT ON: Council-managed personal budgets

Over 80% of older people opt for their Council to manage their personal budget, which is then used to pay for Council-commissioned services, most commonly home care. Research shows less positive outcomes than for older people with cash direct payments. How can these outcomes be improved?

- Councils need to ensure that they have framework agreements with enough home care agencies so there is sufficient capacity and older people's preferences can be accommodated. Particular attention may be needed to ensuring capacity in rural areas.
- Home care agency managers are now often responsible for drawing up detailed support plans with older people, but training for this new role is variable. Councils may need to offer support planning training, as well as information about other local resources and services to home care agency managers. Councils may also need to encourage home care agencies routinely to offer low level choices to older service users.
- Blanket Council restrictions on what personal budgets can be used for are incompatible with the principles of choice and control underpinning personalisation. **So long as any risks are addressed, older people should be able to use managed personal budgets for domestic tasks or social activities, as well as personal care**.
- Wider use of Individual Service Funds (ISF) should be promoted. ISFs involve a contract between the Council and home care agency, but day-to-day arrangements – including the duration and timing of visits – are agreed directly between the service user and provider. Changes in the content of support plans – the tasks undertaken – can also be made without requiring Council approval.
- Where ISFs are not in operation, home care provider agencies and older people should be able to agree relatively small changes to care plans without needing Council approval.
- Time banking should be promoted more actively among older people with managed personal budgets and home care providers, so that home care visits cancelled, for example, because of respite or hospital admission, can be used at a later stage. Again this flexibility is compatible with the principles of personalisation.

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Paying for social care – lessons from other countries

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Key messages

England's current system of means-tested social care funding has been criticised as confusing, unfair and unsustainable.

Other countries have opted for different funding approaches, including social insurance, free personal care, and systems involving private insurance – each has strengths and weaknesses.

Reforms in England from April 2016 will introduce a new £72,000 lifetime cap on the maximum personal liability for eligible care costs, thereby removing the risk of catastrophic loss and increasing the number of people receiving some publicly funded care.

Social care in England, unlike health care, is not automatically provided free of charge to those needing support. People with savings above a specified limit (currently £23,250) are ineligible for publicly-funded social care, and those below this threshold may still have to pay part, or all, of their care costs, depending on their wealth and income.

This 'safety net' system has been the subject of several critical reviews over the past 15 years, and judged to be confusing, unfair and unsustainable[1 2 3]. **While a safety net assists those least able to fund their care, it fails to spread the financial risk**. This means that individuals with high care needs potentially face 'catastrophic' costs that can exhaust their life savings or force them to sell their home. Overall the means-tested approach penalises those who have saved for old age.

Across the developed world, other countries have made different choices about how to fund social care. These include:

- social insurance (similar to the UK's National Insurance system, but with contributions 'ring-fenced' for social care);
- tax-funded systems without means testing (like the NHS funding system);
- safety net systems aimed at those least able to afford care;
- systems involving private insurance for long term care costs; and
- mixed systems that combine two or more of these options.

So long as differences in national culture and preferences are recognised, the experiences of one country can be helpful in informing developments in another[4].

Germany introduced a social insurance system in 1995, making long-term care insurance compulsory, either through the state scheme or private insurance. Employees and employers pay income-related contributions and eligibility and benefits are defined nationally. Almost everyone is included, the risk is shared and there is clarity of what financial support an individual can expect. However, disadvantages include the limited scope to raise benefits without raising contributions and the need for tightly defined eligibility rules that may hamper flexibility when deciding an individual's entitlement to public subsidy.

Scotland introduced tax-funded free personal care for older people in 2002. This removed means testing for home care, and introduced a universal weekly payment for residential care costs (although care home 'hotel' costs covering accommodation, food and energy bills are still means tested). Free personal care removes the risk of catastrophic costs, but is expensive. The main beneficiaries in Scotland have been people with dementia (and others who need many years' support) and those with modest means; however, the reforms proved more costly than expected[5]. A number of countries, such as Sweden, Norway and Finland, have universal systems funded from national and/or local tax revenues but also make charges to users[6].

Japan in 2000 introduced a scheme funded by a combination of general taxation and compulsory insurance contributions paid from the age of 40. There is no means test but service users must pay 10% of their care costs (up to a ceiling). Contributions and benefits are defined nationally and there is no cash option. The system has achieved broad coverage and reduced the burden on family carers, but is not seen as financially sustainable given the ageing population.

The market failure in long-term care insurance, and the lack of other ways to avoid the risk of unlimited care costs, was key to the Government's decision to implement the principles of the Dilnot Commission's 2011 recommendations.

France and Israel have publicly funded systems supplemented by optional private insurance. Private long term care insurance often works in countries where it is part of an employer-based group scheme and/or there is a tradition of private health insurance. The current French system, introduced in 2002, is funded by general taxation, with national eligibility and means-testing rules. Public assistance declines sharply with income, with the co-payment rising as high as 90% of the care package. Private long-term care insurance is relatively popular for augmenting the state offering; France has the second largest market (after the US) for private long-term care insurance, with around 3 million policyholders.

Private long term care insurance has proved less successful in the UK. Demand for insurance against possible future care costs was low, in part due to high premiums, and insurers withdrew from this market. The only type of product still available is an annuity purchased with a lump sum at the point of needing care – an 'immediate needs annuity'.

This market failure, and the lack of other ways to avoid the risk of unlimited care costs, was key to the Government's decision to implement the principles of the Dilnot Commission's 2011 recommendations[7], subject to Parliamentary approval. From April 2016, there may be[8].

- a £72,000 lifetime cap on the maximum amount an individual will pay towards assessed social care needs (not including up to £12,000 a year care home 'hotel' costs)
- an increase in the assets threshold to £118,000 for the residential care means test when the house is taken into account in the means test
- annual 'care account' statements that record progress towards the cap or qualification for additional financial support
- a not-for-profit 'deferred payment' scheme, whereby the local council pays a person's residential care fees and is refunded (with interest and charges) from their estate.

The reforms remove the risk of catastrophic loss and may encourage individuals to plan for old age. Around 115,000 more care service users are expected to benefit from public funding by 2030, compared to the current system continuing, at an additional state cost of around £2 billion[9].

The biggest financial gains will be among care recipients with incomes in the top one-fifth of the income distribution. While the reforms have been welcomed, there will also be practical challenges for commissioners and providers. For instance, local authorities will face increased demand for assessments from people entering the capped system and for the new 'care accounts'.

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Individuals with high care needs potentially face ‘catastrophic’ costs that can exhaust their life savings or force them to sell their home.

Involving older people in evaluation and research

Key messages

Older people truly know about their lives first hand. They are in the best position to share what works for them or does not.

Involving people in research helps get the most cost-effective policy and provision, because it helps ensure that attention is paid to the issues that really matter to the people the service is intended for.

But, while older people are the largest group of users of services, they are the least involved in efforts to determine what has been or will be useful and effective for them.

In recent years, governments have increasingly emphasised that public policy and provision must be evidence based. Essential to this is that they are evidence or *research-based* and key to the best research is that it draws upon the wisdom and knowledge of older people themselves.

This is reflected in increasing efforts made to involve older people as ambassadors of their knowledge and experience in schools, museums and colleges, where they can share with the rest of us what they have learned from a lifetime of experience. Older people alone truly know about their lives first hand. They are in the best position to share their 'experiential knowledge' and they want to. They are our link with our history and our pasts. They can tell us about things that once worked as well as old errors. And there are few places where that knowledge is more important than in research since it can improve the policies and support that may impact on their lives.

Research is a word that is sadly still unfamiliar to and frightens off many people, but all it means is trying to add to our knowledge in a systematic and careful way. Research and evaluation of course are important for developing resources and support for older people. A really exciting and fruitful idea that has been developing recently has been that of involving people who are the focus of research in the research themselves. Many research commissioners and funders now require such public, patient and user involvement, or PPI as it has come to be called, and the government has established the National Institute for Health Research INVOLVE programme to advance such involvement in health, public health and social care research[1].

Involving people in this way is likely to help get the most cost-effective policy and provision, because, instead of focusing on the things

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that may interest researchers, politicians or policymakers, it helps ensure that attention is paid to the issues that really matter to the people that the policy or provision is intended for. This is an important message for all concerned with improving the lives and safeguarding the rights and needs of older people, not least service providers and commissioners. Yet, while older people are the largest group of health and social care service users, they have also tended to be one of the groups so far least involved in research and evaluation. This needs to change.

Three strong arguments for involving older people in research have been identified[2]. First, the importance of including a 'user' or 'consumer' perspective to make services more responsive. Second, the growing view that this improves the quality of research. Finally, the emergence in recent years of social movements, including the movement of older people, asserting their right to be active participants, not only in policy making and service provision but also in research too. So involving older people in research is a matter of human rights; a way of ensuring that research benefits from older people's own understandings and expertise and a means of strengthening their inclusion, rather than reinforcing their exclusion in society.

Involving older people in research has moved on a long way from just expecting them to answer the researcher's questions. Instead it can mean them asking the questions, carrying out the research, analysing and writing it up. Older people can be involved right from the start, working out what questions they think need to be asked, asking the questions themselves, through to sharing or disseminating the findings, as a basis for follow-up action. Involving older people in research is a great way of ensuring that the results don't just gather dust on a library shelf. We know from experience that they will be a force for trying to ensure that change happens as a result of their participation.

If you want to address the issues that really matter to older people, then start by finding ways to involve them. A quick and effective way of doing this is by organising a focus group or small scale consultation with older people to check out their concerns and priorities as a prelude to any further action or research.

There are already much more developed examples of involvement in research to build on. One such is a co-operative of older people, Older People Researching Social Issues (OPRSI), who have both carried out their own research and collaborated with other researchers. For example, members of OPRSI carried out a user controlled research project exploring older people's perspectives on the role and importance of hospital visiting[3].

Another much larger initiative is Shaping Our Age (a partnership with the Royal Voluntary Service, formerly WRVS), in which older people were fully involved in undertaking a major UK-wide research and development project, funded by the Big Lottery Fund, to explore older people's own understandings of their 'well-being' and how they could be more involved in improving it. One of the most exciting aspects of this project was that it established the 'Older People's Reference Group'. This was made up of a diverse range of well networked and committed older people from the four countries of the UK, who made sure that older people's involvement and perspectives were paramount in shaping and undertaking the project and who then pressed for change building on its findings, meeting with Ministers and sharing their findings locally with key stakeholders including other older people[4].

Involving older people in research and evaluation also provides a route into user led commissioning – that is, commissioning shaped by older people themselves and their preferences. This is key to developing the personalised approach to policy and support at the heart of modern health and social care policy aspirations. Finally, it is important to work to involve older people in all their diversity in research – including those who are younger and very old, those living in residential services and their own home (and even prison), and addressing issues of gender, sexuality, culture, class, ethnicity and belief[5]. Here lies the route to sustainable services for older people that they will value and have a real stake in.

For further reading,
see *Shaping Our Lives* publications:
http//www.shapingourlives.org.uk/ourpubs.html

If you want to address the issues that really matter to older people, then start by finding ways to involve them.

[1]www.invo.org.uk

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So involving older people in research is a matter of human rights; a way of ensuring that research benefits from older people's own understandings and expertise and a means of strengthening their inclusion, rather than reinforcing their exclusion in society.

Perfect Ageing: The contribution of assessment

Key messages

Systematic approaches to assessing needs relating to health, independence and well-being offer useful support to older people.

It is useful to segment assessment approaches into different levels, depending on the levels of complexity of needs.

A fully engaged population of older people and local agencies working towards these ends has the potential to create the conditions for perfect ageing and a better future for us all.

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Introduction

As we get older we accumulate threats to our health, independence and well-being, but we vary in how we respond to these threats. When we examine patterns of ageing in later life, some people experience premature loss of health and early death, whereas others age more successfully and enjoy high levels of independence in spite of living to a great old age.

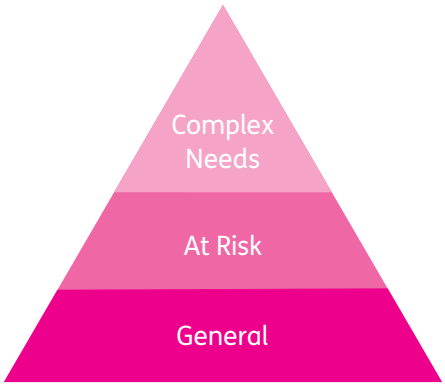
It is within our grasp to intervene with medicine, change behaviour and adapt our environment to achieve best possible health, independence and well-being in later life. **Perfect ageing means achieving the maximum benefits from these potential interventions for an individual**. To do so requires comprehensive, systematic assessment of needs and targeted intervention.

There is a well-developed science of comprehensive assessment of older people which has been applied mainly to the care of frail older people by old age specialist teams. The principles of comprehensive assessment can be applied to older people who are less frail. There is a great opportunity to

maximise health, independence and well-being in later life by using assessment science in this much larger group of older people.

While every older person is unique, it is helpful to think of three different groups as we develop our systematic approaches to assessment (Fig. 1).

Figure 1:
Segmenting the older population



Assessment in the general population of older people

Using the UN definition of old age starting at the age of 60, the purposes of assessment in the general population of older people will be about planning for later life through enhancing sources of self-esteem, ensuring control and autonomy, strengthening social networks, maintaining sound finances and living in an appropriate environment conducive to good health and independence.

A life review at the age of 60 would offer people the opportunity to lay the foundations of a successful old age by focussing on these factors and building them in to encourage behavioural change in relation to exercise, diet, alcohol consumption and smoking. At the same time, it is cost effective at this age to screen for risks to health, including cardio-vascular risk factors such as high blood pressure, high cholesterol and heart rhythm problems, cancer screening for breast, cervical, prostate and bowel cancer and assess bone strength for risk of osteoporosis.

Assessment in at-risk older people

For many older people, paying attention to these environmental, behavioural and medical factors is sufficient to ensure long and healthy life. However, a large minority of older people by the age of 75 will be experiencing significant threats to their health, independence and well-being through the accumulation of medical conditions and changes to their circumstances and relationships. For this group, it is important to undertake a more detailed review of risks and intervene early for those that are of greatest concern.

For the last 25 years I have been working with colleagues to develop a better system of assessment for at-risk older people, which can be applied in primary and community settings (www.easycare.org.uk). This system has been shown to be valid and reliable for use in poor, middle income and rich countries throughout the world (Olde-Rikkert et al., 2012). It covers 49 threats across seven domains: seeing, hearing and communicating; looking after yourself; getting around; housing and finances; safety and relationships; mental health and well-being; and staying healthy.

In our recent studies we have found that the three top concerns of older people assessed by Age UK coordinators were: bodily pain, loneliness, and concerns about memory loss. This information helps us develop services that match older people's needs and concerns. Of course, concerns vary across settings and countries and change over time, but by using a systematic approach to assessing needs and priorities, we are much better able to target our resources and develop services to best meet older people's needs, both for individuals and for populations.

Perfect ageing means achieving the maximum benefits from these potential interventions for an individual.

Assessment in older people with complex needs

A small proportion of older people have a complex set of needs leading to high use of hospital services, a need for support with activities of daily living from families and formal services, and a high risk of institutionalisation. Older people in this group usually have multiple long-term medical conditions, take a large number of medications, and have poor physiological reserves leading to high risk of falls and confusional states. They require a comprehensive approach to assessment.

An effective service response will encompass preventive care, medical diagnosis and treatment, physical rehabilitation, environmental adjustment, support for family carers, attention to mental health needs, the provision of formal services, and end of life planning. The systematic process of assessment, intervention and review through the coordinated work of multi-disciplinary professionals and multi-agency organisations has been described as "comprehensive geriatric assessment" and is the foundation of specialist practice in the care of older people. Numerous studies have shown that this approach is cost effective by reducing long term needs when targeted on older people with complex needs.

Conclusion

Systematic approaches to assessing needs relating to the health, independence and well-being of older people offer great scope to support older people to achieve their perfect ageing potential. These approaches can be segmented into those which should apply to all older people, those which should be targeted on older people who are experiencing threats to their health, independence and well-being, and those which should be applied to older people with the most complex needs.

Health and Wellbeing Boards are well placed to promote perfect aging strategies for the general population. Primary health care, social care and the voluntary sector working together are best placed to identify and respond to the health and care needs of at-risk older people. Old age specialist services should lead the assessment and response for older people with complex needs.

A fully engaged population of older people and local agencies working towards these ends has the potential to create the conditions for perfect ageing and a better future for us all.

Olde-Rikkert, M. G., J. F. Long, and I. Philp, 2012, Development and evidence base of a new efficient assessment instrument for international use by nurses in community settings with older people: Int J Nurs Stud.

In our recent studies we have found that the three top concerns of older people assessed by Age UK coordinators were: bodily pain, loneliness, and concerns about memory loss.

Preventing social isolation and loneliness among older people

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Key messages

Older people are especially vulnerable to loneliness and its negative effects on health and wellbeing.

One-to-one services have been shown by research to be effective, as have some group interventions.

Community Navigator schemes are good at identifying older people at risk of loneliness.

Befriending services can be a cost-effective way to reduce loneliness and depression.

What is the issue?

There are a number of population groups vulnerable to social isolation and loneliness, e.g. young care-leavers, refugees and those with mental health problems. Nevertheless, older people, as individuals as well as carers, have specific vulnerabilities owing to loss of friends and family, loss of mobility or loss of income. It is estimated that, across the present population aged 65 and over, between 5 and 16 per cent report loneliness, while 12 per cent feel socially isolated[1]. Such figures are likely to expand with increasing family dispersal and growing numbers of older people and the 'older-old' – those aged 80 and over[2].

Why is it a problem?

Social isolation and loneliness impact on quality of life and wellbeing, with demonstrable negative health effects. Being lonely has a significant and lasting effect on blood pressure, with lonely individuals having higher blood pressure than their less lonely peers. Such an effect has been found to be independent of age, gender, race, cardiovascular risk factors (including smoking), medications, health conditions and the effects of depressive symptoms[3]. Loneliness is also associated with depression (either as a cause

or a consequence) and higher rates of mortality[4]. The influence of social relationships on the risk of death has also been demonstrated to be *comparable with* well-established risk factors for mortality such as smoking and alcohol consumption, and to exceed the influence of physical activity and obesity. **Such negative impact on individuals' health leads to higher health and social care service use**, while lonely and socially isolated individuals are more likely to have early admission to residential or nursing care.

Given such individual wellbeing, health status, financial and wider community impact, it is clear why there is a national and international consensus to tackle social isolation and loneliness. What is less clear is which effective interventions need to be initiated and supported.

Types of interventions

The variety of interventions for addressing social isolation and loneliness can be classified as:

- One to one interventions (befriending, mentoring and gate keeping including Community Navigators). Befriending involves volunteers or paid workers visiting an individual in their own home (or place of care) with the aim of developing relationships over time, providing social support and often helping with errands and transport. With mentoring, any social relationship that evolves is incidental. Instead, the objective is for the volunteer and the individual to work together to achieve agreed goals and for the individual to develop the skills to sustain any achieved change. Community Navigators work with vulnerable or 'seldom heard' groups, helping individuals to find suitable support or services for them within the local community.
- Group services, including day centre type services such as lunch clubs and social group schemes.
- Wider community engagement, which includes programmes that encourage people to increase participation in existing activities and services such as sport or libraries.

How successful are the different interventions?

In terms of *reducing loneliness*, there is evidence that people using Wayfinder and Community Navigator services became less lonely. One to one befriending also appears to work well. The evidence is more mixed for group activities. On one hand, research identified groups that worked well at reducing loneliness[5] including one 'closed group' and one activity group that included art, discussions, exercise and group therapy. On the other hand, research on a community choir[6] in the United States found loneliness was only slightly reduced and there was little difference in terms of loneliness between people in the choir and those in a 'control' group.

Loneliness is also associated with depression (either as a cause or a consequence) and higher rates of mortality[4].

In terms of *improving health and wellbeing*, **befriending schemes again performed well, demonstrating a significant effect on reducing depressive symptoms**[7], resulting in similar outcomes seen in conventional treatments for depression, such as counselling.

A number of group initiatives have also performed well in terms of improving health and wellbeing. Although the group choir had little effect on loneliness, it seemed to reduce falls among participants. People using a cultural activity group reported improved subjective health and,two years after attending, mortality rates were significantly lower among participants compared with the control group.

Mentoring initiatives do not appear to perform terribly well in terms of improving health. A community mentoring service designed to restore older people's self confidence and self-esteem failed to achieve improvements in depressive symptoms and in fact poorer health outcomes (health-related quality of life) were found in mentoring participants compared with a control group.

Finally, in terms of *reducing health or social care service use*, a psychosocial group rehabilitation intervention (involving art, exercise and discussion)[8] showed good results. Group participants used fewer hospital bed days, saw their GP less and had fewer outpatient appointments compared with people who had not used the service.

What does this tell us?

The wide variety of interventions and the different ways of measuring successes makes it hard to be certain what works for whom. We should focus on what we do know: that Community Navigator interventions are effective in identifying people who are lonely and isolated, and that befriending services can reduce depression and alleviate loneliness, and can be cost-effective. We also know that people enjoy the flexibility that one to one interventions can offer and that satisfaction with group activities could be improved if they were tailored to people's preferences.

The onus for tackling loneliness and social isolation through user-focused models lies with health and wellbeing boards and local community and family networks. Although this represents a significant challenge, the potential benefits for individuals, the community and the welfare economy are self-evident.

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[4]Holt-Lunstead, J., Smith, T. and Layton, J.B. (2010) 'Social relationships and mortality risk: a meta-analytic review', PLoS Medicine, vol 7, no 7, doi:10.1371/journal.pmed.1000316

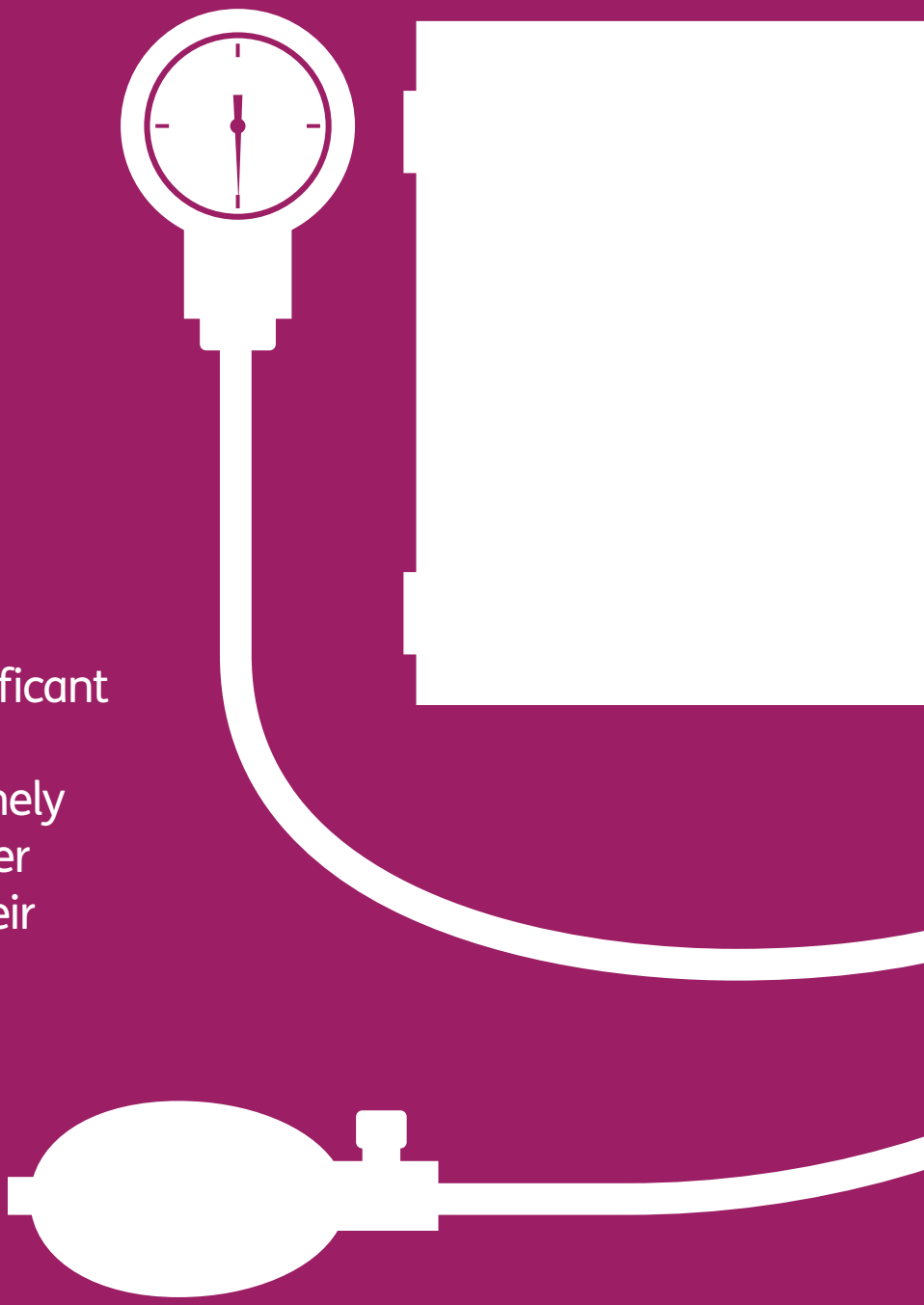
[5]Findlay, R.A. (2003) 'Interventions to reduce social isolation amongst older people: where is the evidence?' Ageing and Society, vol 23, no 5, pp 647–658.

[6]Cohen, G.D. et al. (2006) 'The impact of professionally conducted cultural programs on the physical health, mental health, and social functioning of older adults', The Gerontologist, vol 46, no 6, pp 726–734.

[7]Kremers, I.P. et al. (2006) 'Improved self-management ability and well-being in older women after a short group intervention', Aging and Mental Health, vol 10, no 5, pp 476–484.

[8]Pitkala, K.H. et al. (2009) 'Effects of psychosocial group rehabilitation on health, use of health care services, and mortality of older persons suffering from loneliness: a randomised, controlled trial', Journal of Gerontolgy: Medical Sciences, vol 64A, no 7, pp 792–800.

Being lonely has a significant and lasting effect on blood pressure, with lonely individuals having higher blood pressure than their less lonely peers.



Promoting older people's inclusion in rural communities

Key messages

Several studies have demonstrated ways that local Councils in partnership with voluntary and other community organisations and service providers can help promote social inclusion of older people.

Facilitating social inclusion for older people in rural communities not only contributes to their health and wellbeing, but also to that of the community.

Lack of transport is a major barrier to participation and social inclusion in many rural communities.

Rural areas in the United Kingdom are experiencing rapid growth of their older populations, and the situation of older people is recognised as crucial to the sustainability of rural communities. The experience of later life in rural places varies significantly, with individual circumstances influenced by features of the rural community context to determine quality of life in older age. **The availability of, and access to, key local services and amenities all affect older people's ability to remain active participants in rural community life**.

Older people's continued engagement in social and civic activities has important benefits for individuals as well as for their communities. Maintaining involvement in leisure pursuits and volunteering, for example, positively influences health and well-being in later life. Likewise, older residents are acknowledged as making significant contributions to the 'social capital' of rural communities through giving their time, expertise and skills to assist local organisations and groups as well as family, friends and neighbours.

The 'Grey and Pleasant Land' (GaPL) study on later life in diverse rural areas in the United Kingdom identified factors that have an impact on older adults' participation in their rural communities[1]. This and other investigations on the inclusion of older rural residents have shown that personal resources and social connections increase the likelihood of an older individual

Maintaining involvement in leisure pursuits and volunteering, for example, positively influences health and well-being in later life.

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being engaged in community life. However, community involvement is also influenced by a sense of community belonging and safety, the availability of local community hubs and services, and the means of getting around in a community (both physically and virtually through the internet).

Lack of access to transport in particular is a barrier to older people's social inclusion in many rural areas. Rural residents need to travel further to access most services and the ability to take part in valued social and community activities is affected by their transport options. Our research found that older rural residents' satisfaction with the extent of their involvement in their communities was significantly related to having a car available in their household. In rural areas where transport services are limited, older people's connections to community life can be compromised.

The GaPL study also presented a picture of rural elders increasingly engaged in the use of modern technologies to meet a wide range of their needs, from staying in touch with family and friends to shopping and pursuing leisure pastimes. This is crucial to the well being of future cohorts of rural elders as we move into a world where access and payment for an ever wider range of services is delivered online. For those with limited resources, however, the risk of digital exclusion is increased.

Innovative rural service approaches highlight how older people's connections with and participation in their community can be maintained and promoted. **Community and social enterprises are a successful means of both engaging older people as volunteers as well as offering needed services**[2 3]. In many rural areas, older people play a key role in running social enterprises like community shops which have been shown to increase community cohesion and social contact among these volunteers. A variety of such low level support strategies have demonstrated the potential to improve participation in social and community activities, increase independence and improve health and well-being for older people living in rural areas.

Affordable demand-responsive transport services, such as Lincolnshire's 'CallConnect' and other community transport schemes such as Dial-a-Ride and Transport Access People in Cornwall and the Isles of Scilly, offer examples of how partnership working between local government, volunteers and charities can successfully meet the transport needs of people living in rural areas[2 4]. In Gloucestershire, the Village and Community Agents scheme uses volunteers to provide older rural residents with up-to-date information about and improved access to local services, as well as support for engaging with social activities in their communities[5].

The social integration of older people in the countryside has also been increased through initiatives such as the Upstream project in rural Devon[6]. This community-driven social enterprise engages older rural residents at risk of isolation through creative and stimulating social activities. As a partnership involving community organisations and statutory and voluntary agencies, the project also assists villages and market towns to maximise the use of existing facilities and community resources to ensure the social inclusion of older people.

Other rural residents and their family carers at significant risk of social isolation are older people with dementia. Innovative initiatives such as the Dementia Friendly Parishes Around the Yealm in Devon – a partnership of rural Parish Councils, local charities and care providers – is raising local awareness about dementia as part of an inclusive community approach for people with dementia and their carers[7].

While national Government has been challenged to commit greater resources to address the problems faced by rural elders, in the current era of fiscal retrenchment rural communities have been at the forefront of developing innovative approaches to meet the needs of their older residents. Many of these initiatives, such as those described, have been informed by and capitalise on the input and contributions of older people as rural community assets. In doing so, they point the way for sustaining rural communities and the well-being of their older residents.

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[2]Le Mesurier, N. (2011) *Growing Older in the Countryside*, Cirencester: Action with Rural Communities.

[3]Plunkett Foundation, Prime, Countryside Agency, Age Concern (2004) *Rural lifelines: Older people and rural social enterprise. Their role as providers and beneficiaries of service provision in rural England*, Woodstock: Plunkett Foundation.

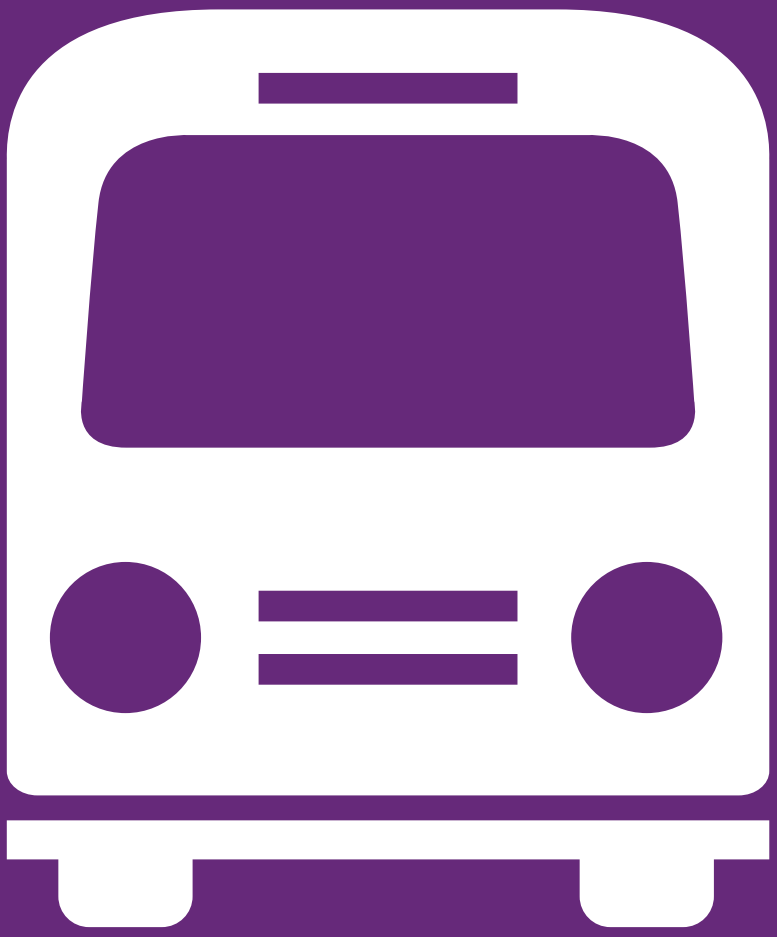
[4]Age UK (2013) *Later Life in Rural England*, London: Age UK.

[5]Wilson, L., Crow, A. and Willis, M. (2008) *Village Agents. Gloucestershire County Council in Partnership with Gloucestershire Rural Community Council*. Overall Evaluation Report, Birmingham: School of Government and Society, University of Birmingham.

[6]http://www.upstream-uk.com/Research-and-evaluation.html

[7]http://www.dementiayealm.org/

Lack of transport is a major barrier to participation and social inclusion in many rural communities.



Housing with care for older people

***Simon Evans**, PhD, is Principal Research Fellow in the Institute of Health and Society at the University of Worcester. His research interests focus on contributing to the evidence base for improving quality of life for older people, including those living with dementia.*

Key messages

Older people living in housing with care report very high levels of satisfaction, particularly in terms of good levels of security and privacy, the availability of flexible care and support, opportunities for social interaction, age-friendly design, access to facilities, and not having responsibility for property maintenance.

Despite this popularity there is a significant shortfall in housing that meets the needs and preferences of older people, including provision targeted at BME older people.

There is a lack of clarity about what 'housing with care' is, partly as a result of the diverse range of models that fall within this housing category.

About housing with care

Housing with care, which in the UK mostly takes the form of retirement villages, extra care housing and very sheltered housing, is a popular option among older people and is sometimes seen as a 'homely' alternative to care homes. Schemes vary considerably but key features include: self-contained flats or bungalows; the incorporation of design features and assistive technology to facilitate independence; the provision of adaptable packages of care in each resident's own accommodation; and the availability of flexible, 24 hour care and support. A growing body of research has explored the potential benefits of housing with care[1 2 3 4]. Residents generally report

Residents generally report high levels of satisfaction for a range of reasons...

high levels of satisfaction for a range of reasons including feeling safe, enjoying independence and control, good access to amenities and social activities, and not being responsible for property maintenance.

The supply of housing with care has increased substantially over the past 20 years and it is estimated that there are 40,000 units of extra care housing and approximately 100 retirement villages in England. However, there is a gap of approximately 25% between supply and demand. This under-provision has implications for the wider housing market, including the current drive to free up larger houses for younger families to use.

Benefits

Much of the evidence for the benefits of housing with care comes from research based on interviews and focus groups with residents, relatives and staff. Some of this work has explored the capacity of housing with care to support people with dementia. The findings suggest that people with dementia living in housing with care have a better quality of life than those in more traditional institutional settings, although they also identify some areas for improvement. These include providing specialist training for staff, increasing tolerance on the part of other residents, and providing a stimulating environment.

One example is an intervention called the Enriched Opportunities Programme[5], which was evaluated in extra care housing using a controlled trial methodology[6]. This initiative adopted a whole scheme approach to supporting people with dementia that included specialist staff, leadership, staff training, individualised care-work, community liaison and the provision of appropriate activities. Those receiving the service were less likely than residents in the control sites to move to a care home or to be admitted to a hospital inpatient bed. They were also more likely to be seen by a range of community health professionals.

There is also a considerable body of evidence[7 8] indicating that the design of the built environment is a key factor in supporting residents who are ageing in place, while poor design can lead to the marginalisation of residents with physical frailties or cognitive impairment. **The provision of a range of facilities and activities is a key feature of housing with care, particularly in terms of supporting independence and promoting social interaction**. There are also many benefits to adopting a community hub model, whereby facilities and amenities within housing with care schemes can be used by people living nearby.

Challenges

Housing with care, particularly extra care housing, covers an increasingly wide range of models; this makes it very difficult for older people and their families, and professionals who work with them, to make good decisions about housing options, particularly at times of crisis. This is exacerbated by a shortage of specialist housing that meets the needs of older people.

The move towards using personal budgets and direct payments presents considerable challenges for extra care housing. For example,

will residents be left without the on-site care element due to their lack of collective bargaining power?

There is a lack of evidence for the benefits of different models of housing with care, particularly in terms of how well it can provide end of life care, the best ways of supporting residents with dementia, and the cost of housing with care compared with more institutional forms of care and support such as care homes.

Developments

The funding models used for developing housing with care schemes and providing the care and support are changing rapidly; this is due to a range of factors, including cuts in public spending and changes in welfare payments. It remains to be seen how these changes affect the level and type of provision.

The coalition government has made available up to £300 million to create accessible homes for disabled and older people who need extra support. Under phase one of this initiative funding has been allocated for 3,500 new homes across England.

There is a growing government focus on supporting older people to downsize, thereby freeing up larger homes for young families. Housing with care has great potential to provide suitable homes for older people who want to make such a move, but the overall lack of age-friendly homes presents challenges for this policy. There may be a case for developing new housing models such as co-housing and home sharing, and greater use of assistive technologies.

The ASSET project[9], funded by the National Institute for Health Research (NIHR) School for Social Care Research, is exploring the commissioning of adult social care in housing with care settings. This work aims to produce much-needed evidence about how to deliver social care in a way that maximises quality of life for residents while also providing value for money.

Local authorities need to consider the housing needs of increasing numbers of older people and the many benefits that housing with care has to offer. These include promoting independence, maximising social integration and supporting couples to live together for longer.

[1]Evans, S & Vallelly, S (2007). Social Well-being in extra care housing. Joseph Rowntree Foundation.

[2]Croucher, K. & Bevan, M. (2010) *Telling the story of Hartfields: A new retirement village for the 21st Century*. York: Joseph Rowntree Foundation

[3]Evans, S. (2009) 'That lot up there and us down here': social interaction and a sense of community in a mixed tenure UK retirement village. *Ageing and Society*, 29(2), February 2009, pp.199–216.

[4]Darton, R., Bäumker, T., Callaghan, L & Netten, A. (2011) Improving housing with care choices for older people: the PSSRU evaluation of extra care housing. *Housing, Care & Support* 14 (3) pp.77–82

[5]www.worcester.ac.uk/discover/dementia-enriched-opportunities-programme.html

[6]Brooker, D Argyle, E., Scally, A. & Clancy, D. (2011) The Enriched Opportunities Programme for people with dementia: a cluster-randomised controlled trial in 10 extra care housing schemes. *Aging and Mental Health*, 15 (8), pp.1008–1017.

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[8]Torrington, J. (2006) What has architecture got to do with dementia care? Explorations of the relationship between quality of life and building design in two EQUAL projects. *Quality in Ageing: Policy Practice and Research*, 7(1), pp.34–48

[9]http://assetproject.wordpress.com/

The findings suggest that people with dementia living in housing with care have a better quality of life than those in more traditional institutional settings, although they also identify some areas for improvement.

Home telecare in practice

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Key messages

Telecare works best if it is part of a wider social network.

Telecare systems anticipate an 'active user' who is able to follow instructions/rules, so are not suitable for people with high level or complex needs.

There are many care tasks that telecare cannot do. Contrary to many expectations, it creates additional work, introducing new tasks, skills and responsibilities.

Telecare, the provision of health and social care at a distance using information and communication technologies, has recently been prioritised in services for older people by government and industry. But how do home telecare systems actually work and what are their social and ethical implications?

We want to ensure that whatever the technology is, it isn't simply replacing the person who is currently giving the care. The huge danger is that if we go down that road to any great extent, it is so easy because of financial implications to reduce the personal input. It is so important not to replace that human contact.

–(Older Citizens' Panel)

There are many care tasks that telecare cannot do: it cannot, for instance, help people to the toilet or clean the house. Telecare does not *perform care* on its own, but becomes part of new forms of caring relations and activities. Contrary to many expectations, it creates additional work, introducing new tasks, skills and responsibilities. New actors include

equipment installers, tele-operators, instructors, service providers and service workers, in addition to family carers, neighbours, friends and volunteers.

Telecare is not a solution, but a shift in networks of relations: telecare does involve different forms of 'human contact'; systems of alarms and sensors do not work effectively if the older person has no social network. Monitoring centre staff reported the continuing importance of immediate family or neighbourly 'contacts' when problems arose. The work of telecare call centre staff, (predominantly women), involves unrecognised complexity and uncertainty and can be stressful. The current expansion of these call centres carries the risk of globalisation of provision and dilution of care quality.

Tasks become redistributed: using telecare systems involves a range of new activities for carers and older people. For example, with wearable GPS tracking devices, relatives of older people living with dementia needed to take on new responsibilities, from charging the batteries in the device to making sure the 'user' remembered to carry it, to making payments and maintaining contact with telecare agents and providers. Telecare shifts care roles and responsibilities: for an older person living alone, the importance of neighbours rather than (necessarily) family members was stressed (neighbours can more easily check on older people and/or let care providers into the home).

Telecare systems assume an 'active user': this is one who is able to follow instructions/ rules. Failure to respond 'correctly' can give rise to confusion or unwanted intrusion. A 'good user' here is one who self-manages, is responsible and plays a part in preventing problems. The projected ideal user is active in certain ways and compliant in others.

Telecare may lead to decreased privacy for older people or may be intrusive: good care sustains privacy and while telecare may enhance this if it enables reduction in home visits, in some situations privacy may be threatened, for instance by movement sensors in the home or devices using GPS tracking. Complex negotiation is called for between loss of privacy and possible increased liberty.

Telecare sometimes offers 'peace of mind': good telecare practice was widely described as reassuring. This is particularly noticeable in the use of alarm pendants: even if the pendant is never or hardly actually activated, its presence can provide reassurance for the older person and her/his family and friends.

Older people living at home often use telecare in unpredicted ways: we found examples of older people refusing to wear their pendants (or being selective about when and where they put them on), or to use monitors, or asking to have systems taken away. Inability to comprehend the system may result in non-use. One client left her falls monitor, designed to be worn around the waist, carefully on the shelf in order not to activate it. In many other cases telecare devices were unused.

Social needs are often ignored in telecare system design: some clients 'over-used' telecare to get social contact with monitoring centre operators. Social care managers and providers, often considered such 'misuse' problematic, yet this may be a sign of increasing isolation and loneliness.

Some informal/family carers 'customise' devices to suit particular needs of individual/ setting: carers also tinkered with the technologies in order to adapt them for their particular situation, such as using matchsticks and tape to ensure that a family member did not accidentally set off their alarm. Some healthcare workers also find it necessary to modify systems. Such 'tinkering' in order to make telecare more efficient, more affordable, or improve workflow, stemmed from real interaction with, and involvement of, older people.

Discussion

Telecare does not offer a 'technological fix' to replace existing health care services or informal care networks: it is not a simple solution to care, personnel or budget crises in ageing societies. **That remote care is particularly effective for people living alone and lacking social**

networks does not appear to be based on evidence[1 2]. Telecare either sustains/develops a network already in place, or must create a new network, drawing on volunteers and family carers. Existing or new care networks can be supported by meaningful consultation with potential 'users', starting from the goals, values and life history of the older person.

Through telecare, responsibilities in care networks are shifted and delegated in new ways. In the case of pendant alarms, users may be made aware of themselves in new ways, enhancing independence. Other forms of home telecare which are more 'passive', or monitoring-based, shift agency away from the older person, where decisions can be taken based on sensor/movement data about which they may be unaware. Telecare also implies new meanings for privacy and confidentiality, both in the collection of data about personal movement, but also that one's home is 'opened' to a range of others who may call, check or visit.

Our study demonstrates the meaninglessness of talking about care technologies in terms of good/bad, effective/ineffective, outside of their context of use; it shows that telecare is not a neutral tool and that the good/bad debate is an oversimplification. Telecare should not be understood as a universal solution, but a situated one. Poor telecare design results in wrong assumptions about the role and identity of the 'user', that older peoples' customisation of devices is both legitimate and often necessary in order to make devices 'work'. We show the importance of recognising telecare's limits, revealed through practice in the face of rather over-optimistic policy.

An ethics of telecare emerges from our work. People's creativity in customising systems and adaptability in using them is essential to the 'ethical' practice of telecare, and these should be respected and accommodated, rather than being seen as a problem. In this way, telecare systems (in design and implementation) might enhance independence and avoid becoming isolating or coercive.

Further reading:

Our study for the European Commission entitled Ethical Frameworks for Telecare Technologies for older people at home **(EFORTT)** examined telecare in practice in England, Norway, Spain and the Netherlands. We observed telecare call/monitoring centres; installation visits to older peoples' homes; telecare training events; and industry, medical and policy-related conferences. We shadowed social workers and other professionals undertaking needs assessments. We conducted interviews with older people who had home telecare systems installed and technology developers and providers, and analysed key policy documents. We also held 22 older citizens' panels where older people and carers drawn from voluntary and community organizations, older people's forums, senior citizen centres and carers' support groups discussed their aspirations for care and technology. The EFORTT final report can be downloaded from www.lancs.ac.uk/efortt

Mort M, Pols A, Roberts C, Domenech M & Moser I (2013), Ethical implications of Home Telecare for older people: a framework derived from a multi-sited participative study, *Health Expectations*. (Early View 06 Aug 2013)

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[1]Steventon A, Bardsley M, Billings J et al, Effect of telecare on use of health and social care services: findings from the Whole Systems Demonstrator cluster randomised trial, *Age and Ageing* (2013) 42 (4): 501–508

[2]Cartwright M, Hirani S, Rixon L et al, Effect of telehealth on quality of life and psychological outcomes over 12 months (Whole Systems Demonstrator telehealth questionnaire study): nested study of patient reported outcomes in a pragmatic, cluster randomised controlled trial, BMJ 2013; 346: f653

Social needs are often ignored in telecare system design: some clients ‘over-used’ telecare to get social contact with monitoring centre operators.

Supporting older people in the community rather than hospital

Key messages

There is strong evidence that some frail older people can be better and more efficiently supported at home or in their care homes than in hospital.

Developing and delivering these services adequately is not simple or cheap.

Close management and scrutiny of delivery and outcomes must be undertaken for success.

Older people are major users of hospitals[1]. This is hardly surprising given that the majority of disease occurs in older people. Neither it is wholly undesirable, as older people should enjoy the benefits of hospital care just as much as people in any other age group. However, there is increasing recognition that many hospital admissions for *frail* older people are unwanted by the patient and the carer, many hospital stays are prolonged by unpleasant and expensive hospital-associated complications and some people appear to achieve little health gain. One option is to improve the quality of care in hospitals, but some of these drawbacks may be almost inevitable. Given this, attempts have been made to seek alternative, community-based, solutions.

Under the broad term '*proactive care*', one approach is to attempt to *prevent* the crises that precipitate emergency hospital admissions. Another approach is to *anticipate* these crises so that alternative provision can be made when they occur. Yet another strategy is simply to *re-provide* hospital services in the community.

Prevention and anticipation

Despite the obvious desirability of preventative services, the evidence that this can be done is poor. On the other hand, there is ample evidence that anticipatory services and services re-providing the community are worthwhile. An example of an effective anticipatory service is the use of a programme to set up advance directives for willing residents in nursing homes. In a large study of Canadian nursing homes, such a programme halved the number of days such people spent in hospital[2]. This programme not only allowed people to choose to die in the care home, but to avoid other non-terminal hospital admissions. It required alternative arrangements for them to be made in the home but, despite this, the cost of the programme was easily outweighed by the savings. Such an approach is now considered best practice in all care homes. The degree to which this approach will achieve similar benefits for people living in their own homes is not so clear as it is harder to ensure that the needs of people who are acutely ill can be met in their own homes even if they would prefer to be managed at home.

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Hospital at home services do not aim to prevent or anticipate episodes of ill health, but simply aim to provide care in the community instead of the hospital.

The Evercare scheme, developed in US nursing homes, also exploited the potential for residents of nursing homes to be managed out of hospital[3]. In Evercare, advance nurse practitioners provided the primary care to care home residents instead of the usual medical response. As in the Canadian advance directive study, it halved the rate of hospital admission and this more than offset the costs of the extra nursing home care provided. Importantly, although the Evercare services aimed to have a preventative role, residents using Evercare experienced the same number of episodes of ill health experienced by those not using Evercare. This is evidence that prevention is difficult to achieve, but provision of care in non-hospital settings is possible.

The benefits of re-provision

In broad terms, two types of re-provision services have been shown to be effective in reducing the use of hospitals for community dwelling people, both "hospital-at-home" services. Hospital at home services do not aim to prevent or anticipate episodes of ill health, but simply aim to provide care in the community instead of the hospital. Two major types of hospital-at-home services are recognised: early discharge and admission avoidance. In the UK, these are usually described as "intermediate care" services, and often they are integrated into one overall service.

A review of 26 high quality studies of early discharge services showed that they reduce hospital length of stay by an average of 7 days when compared to usual hospital care[4]. Most users were older people. There was also a 37% reduction in the risk of going into a care home in those in early discharge services and patients in early discharge services were more satisfied. There was no other difference in health outcomes, so they did not put patients at risk.

A review of 10 high quality hospital-at-home studies, of services to provide care at home for people who would otherwise be admitted to hospital, showed them to lead to a **38% reduction in the risk of death over the next six months, an average saving of 14 hospital days per patient despite a 49% increase in readmissions, a markedly reduced risk of people with dementia going into an institution (by 89%), higher levels of patient satisfaction and lower costs to the health and social systems**[5].

These two reviews therefore provide powerful evidence that providing care at home for older people who would otherwise be in hospital is possible, desirable and worthwhile. Re-provision of community care instead of hospital care does more than mere diversion of patients from one setting to another. Admission avoidance appears to be the best value in terms of health benefits and savings, but the approaches are complementary rather than mutually exclusive.

Some caveats

The research evidence base only tells part of the story. It shows what can be achieved within the conditions that apply within research trials. It justifies health service commissioners and providers in developing diversionary schemes for admission avoidance and early discharge. But care must be taken not to think that developing and delivering these services is simple or cheap. Great care is taken in the setting up of services in research studies, to their close management and scrutiny of their outcomes: if this is not replicated in ordinary clinical practice then the outcomes may not be as good. As an example, since early discharge services save an average of 7 hospital days, an underprovided service that develops a 7 day waiting list will wipe out all the benefits. Also, research services often attract enthusiastic pioneers who may not reflect the bulk of practitioners. Research services are often set up without having to consider the practical issue of sustaining and embedding services beyond the trial end point. Care has to be taken to develop and maintain a skilled workforce.

Conclusion

The good news is that there is strong evidence that some frail older people can be better and more efficiently supported at home or in their care homes than in hospital. There is an urgent need to develop these at scale and pace.

[1]Age UK Later Life Factsheet. http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true

[2]Molloy DW, Russo GH, Goeree R, et al. Systematic implementation of an advance directive program in nursing homes. A randomized controlled trial. JAMA 2000;283:1437–44.

[3]Kane RL, Keckhafer G, Flood S, Bershadsky B, Siadaty MS. The effect of Evercare on hospital use. JAGS 2003;51:1427–34

[4]Sheppard S, Doll H, Gladman J, Iliffe S, Langhorne P, Richards S, Martin F, Harris R. Hospital at home early discharge (Review).Cochrane Database of Systematic Reviews 2009 Issue 1. Art. No.: CD000356. DOI:10:1002/14651858.CD000356.pub3. http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD000356.pub3/otherversions

[5]Sheppard S, Doll H, Angus RM, Clarke MJ, Kalra L, Ricaunda NA, Wilson AD. Hospital at home admission avoidance (Review). Cochrane Database of Systematic Reviews 2008 Issue 4 Art. No.: CD007491. DOI 10:1002/14651858.CD007491.

http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007491/abstract

A review of 26 high quality studies of early discharge services showed that they reduce hospital length of stay by an average of 7 days when compared to usual hospital care[4].

Men in Sheds

Key messages

There are some specific gender differences which make targeted interventions for men necessary.

There are fewer services available for men and they are less likely to take part.

Gender-specific services such as Men's Sheds provide a safe space for older men.

Older men can derive a wide range of benefits from targeted schemes.

Introduction

The life expectancy gap between older men and women is closing and the ratio of older men to women is projected to rise from the current position of 100:127 older men to older women, to 100:118 in 2035. But social isolation is also rising amongst this group, particularly for lone-dwelling older men, or those who experience mood or cognitive problems. **Social isolation and loneliness are known to impact adversely on a range of physical and mental health conditions as well as recovery from illness**. Indeed, amongst older adults, the effect of social isolation and loneliness on mortality has been compared to that of cigarette smoking.

Meeting the needs of older men is thus an important, but often overlooked, public health issue. It is well recognised that older men use fewer community-based health services than women, and are less likely to participate in preventive health activities. They also find it harder than women to make friends in later life, and are less likely to join community-based social groups that tend to be dominated by women. The reluctance of older men to engage with services and activities; growing rates of social isolation and loneliness; and the poorer health-seeking behaviours of men compared with women places older men at greater risk of physical and mental ill-health. The lack of a co-ordinated response to these issues from statutory services has been met by a range of interventions developed by the third sector and targeted at older men. **Men in Sheds provides one example of 'what works'**.

What is a Shed?

Originating in Australia in the 1990s, the Shed 'movement' has grown rapidly across a number of countries stretching from Australia and New Zealand to North America and Europe. There are now more than 800 Sheds in Australia and more than 100 Sheds across the UK and Ireland. Men's Sheds comprise voluntary and social

Sheds provide a space where older men meet, socialise, learn new skills and take part in activities with other men.

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spaces that provide hands-on activities – mainly but not exclusively – to men aged 50 years and older. Sheds can be run entirely by volunteer members, but many have a paid co-ordinator whose role is to encourage recruitment, facilitate activities and provide support to those older men who may have some level of physical or cognitive disability. Importantly, participants are defined as members not service users. A number of Sheds in the UK have also been developed as Community Interest Companies (CICs), hence have a specific remit to operate for the benefit of the community.

Sheds provide a space where older men meet, socialise, learn new skills and take part in activities with other men. The space can vary from a domestic garage, a room in a community centre or similar, to a disused industrial unit. Importantly, Sheds are developed 'bottom up', with Shed members deciding on what activities should be undertaken. In almost all cases, they are tailored to their local context, rather than being standardised. Most Sheds are equipped with a range of workshop tools but others involve model railways, bicycle or car maintenance, model engineering, upholstery, blacksmithing and making musical instruments.

How do Sheds engage older men?

Beyond any CIC remit, Sheds are designed to encourage and engage older men in informal adult learning and social interaction. The evidence base places particular emphasis on the ways in which Sheds facilitate peer learning, and the learning of new skills in a 'work-like' setting but devoid of the pressures of the workplace.

Sheds also aim to improve older men's physical, emotional and social health and well-being. Some Sheds (mostly those that are externally funded) also provide health-related information and signpost men to relevant services (for example, health screening and health promotion, welfare services, counselling etc.).

The role of Sheds in contributing to health and wellbeing has been acknowledged in recent health policy documents in Australia and Ireland. However, great variation in Sheds exists, so it is important to identify the core components that make them successful as a gender-specific social activity intervention.

What works – the evidence base

While there is some limited evidence to suggest that older men's *physical* health might be improved by participating in Men's Sheds, it is largely based on self-report and, as yet, there is no longitudinal or measurable evidence to demonstrate that involvement in Men's Sheds has a significant positive impact on the physical health of older men. The evidence for a positive effect on older men's *mental* health, however, is more extensive. Whilst also based on self-report, there is remarkable consistency in the evidence base to indicate that the impact is predominantly mediated through cognitive stimulation and meaningful contributions to the community.

There is a general consensus within the evidence base that the provision of a physical Shed space for older men to meet and interact can provide an array of benefits for those at risk of social isolation, including facilitating:

- a sense of purpose through learning new skills and sharing knowledge;
- a sense of accomplishment and self-worth through personal achievement and contributing to the wider community;
- a sense of control through co-participation in decision-making and activities;
- an improvement in self-esteem, sense of self-worth and self-image, making older men feel positive and valued in society; and
- the provision of a sense of community, belonging and 'kinship' with other older men.

One additional benefit of Men's Sheds is the provision of an environment in which older men can share their health concerns and experiences in a supportive forum, in what can be referred to as 'health by stealth'.

Community-based Men's Sheds are generally regarded as welcoming and tolerant places for older men from a wide range of socio-economic backgrounds. For many members, contact with a wide cross-section of society is seen as a valued benefit of attending a Shed. There is only limited evidence of the extent to which Sheds meet the needs of older men from ethnic and minority backgrounds, but that which does exist indicates that, though Sheds appeal to older men from a range of minority ethnic backgrounds, particular thought needs to be given to Shed location, i.e. Sheds need to be located *within* the particular minority ethnic community they are seeking to target.

As most Sheds are formed and operate at 'grass-roots' local level, they are largely accessible to all older men. Indeed, some of the key characteristics of 'successful' Sheds are autonomy, inclusiveness and accessibility. This refers to a physical and organisational structure that allows full participation in all aspects of (Shed) activities; provides meaningful opportunities to become involved in decision-making processes; and links with the wider community.

The evidence suggests that, for some older men, Shed participation can be a life-changing enabler for recovery from depression, or drug

The evidence suggests that, for some older men, Shed participation can be a life-changing enabler for recovery from depression, or drug and alcohol addiction.

and alcohol addiction. **For older men with dementia or other cognitive or physical disabilities, hands-on, shed-based experiences are regarded as positive, therapeutic, educative and transformative. Some evidence suggests that Men's Sheds can provide an important 'lifeline' for older men with early stage dementia and their families**.

Although most research focuses primarily on the older men's experiences rather than the well-being and quality of life of their caregivers, those few studies that have considered informal carers noted that the majority of carers reported a positive impact on their relationship - one study noting that there was evidence of the older men's increased happiness, interest in the family and help with household chores.

The practical elements of 'what works' to make a successful Shed include: a suitable and accessible location; the provision of a wide range of activities; extended opening hours; strong local support; secure funding; a sound business plan; a skilled manager and management group; an opportunity to learn from other Sheds and affiliation to a Shed support network early in a Shed's development. Some research also suggests that Shed members feel comfortable when Sheds are run in relatively unstructured and informal ways and that this enables the Shed to move beyond a place of activity to become a place of belonging, friendships and purpose.

Sustainability

Financial sustainability varies depending on the model of intervention developed. Some small 'grassroots' Sheds rely on donated/personal premises, voluntary contributions and the sale of items made by Shed members to offset operating costs. Other Sheds are reliant on time-limited external funding, raising issues of long-term sustainability. The first model relies on volunteers so is less able to support older men with higher support needs. The latter operate with paid coordinators. While more costly, this model is able to support participation from older men with disabilities and/or early stage dementia or other mild cognitive impairment, providing opportunities for paid care placements. In Australia, there has also been a move toward government supported 'volunteer' placements in Sheds for unemployed men.

Concluding comments

The evidence suggests that Men's Sheds provide a safe space for older men to participate in purposeful physical activities on a voluntary basis. Activities can be broad-ranging and are decided upon by Shed members. Activities can involve the learning or sharing of skills that can be performed individually or collaboratively and the products of members' 'work' may be for personal use or community projects. More common products are sold – the funds either being used to offset some operating costs or donated to charity. The opportunity to 'give back to the community', either financially or 'in kind', contributes to older men's sense of achievement, accomplishment, value and altruism.

Sheds also create and foster social interaction and connections, and a sense of camaraderie for older men who may experience a loss of identity on retirement and social isolation. Consequently, gendered interventions such as Sheds can provide older men with an activity that is acceptable, accessible and effective in addressing their social and wellbeing needs.

Finally, while there have been a number of evaluations of Sheds, as yet, none have used a longitudinal design or validated measures to assess improvement in health and/or wellbeing. Most rely on self-report. Despite this, there is a remarkable consistency of outcome in an evidence base that stretches across countries ranging from Australia to Canada, Ireland and the UK. So while a robust longitudinal evaluation would be desirable, it seems justifiable to say that Shed-type activities can play a significant role in addressing social isolation, supporting community engagement and providing continued learning opportunities for older men – with the added bonus of contributing to improved health and wellbeing.

Acknowledgement:

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Amongst older adults, the effect of social isolation and loneliness on mortality has been compared to that of cigarette smoking.

SPOTLIGHT ON: Services for men

***Christine Milligan**, BA(Hons), PhD, is Professor of Health and Social Geography and Director of the Centre for Ageing Research at Lancaster University.*

Older men's health is an important public health challenge. Men's mortality rates are higher than women's and the number of potential life years lost by men is double that for women. But many of the causes of excess mortality amongst men are avoidable or amenable to treatment.

Older men use fewer community-based health services than women, and are less likely to take part in preventive health activities. They also find it harder than women to make friends in later life, and are less likely to join community-based social groups that tend to be dominated by women.

Finding acceptable social interventions for lonely and isolated older men, particularly those from lower socio-economic backgrounds, is a challenge. In the absence of a co-ordinated response from statutory services, a range of interventions have been developed by the third sector. 'Men in Sheds' is one example of an intervention that is rapidly growing across a range of countries.

Participation in a Shed, a community garden or other activity is linked to older men's desire to engage with their peers in work-like activity. This gives them a sense of identity, self-esteem and value.

Though designed primarily as a learning and activity intervention, some Sheds provide 'signposting' to other services (such as health checks, welfare support, counselling services etc.). One example is the 'Shed Weight' programme in which Shed members are encouraged to eat healthily and control weight.

The success of these interventions lies in a 'health by stealth' approach in which improving health is not overtly promoted as a core goal to older male participants.

Financial sustainability varies depending on the model of intervention developed. Small 'grassroots' Sheds operating on voluntary contributions and the sale of items made to offset operating costs can be self-sustaining but are less able to support older men with higher support needs. Sheds reliant on external funding, with paid coordinators are more costly, but are able to support participation from older men with higher-end support needs, including disability and/or early stage dementia.

Men's Sheds and other gendered interventions provide a safe space for older men to participate in purposeful physical activities on a voluntary basis. They also provide a range of other benefits including: learning new skills, sharing knowledge, personal achievement, community engagement, and the opportunity to meet and interact with others. Many of these are reported to impact positively on mental health and well-being. See the chapter on Men in Sheds for more.

Preventing falls with older people living in the community

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***Charlotte Brooks**, BSc, PhD student at the University of Southampton and occupational therapist working in a community team within Solent NHS Trust. Currently undertaking research exploring health literacy and falls in older people.*

Key messages

Falls can cause significant challenges for older people and society.

However, they are not an inevitable part of old age, and can be prevented or reduced.

Comprehensive risk assessment and evidence based interventions delivered by appropriately qualified professionals can reduce both the rate of falls and risk of falling.

The meaningful involvement of older people in falls prevention will increase its likelihood of success.

Introduction

'... I didn't put the light on as I entered the kitchen and just went and hit my face on the work surface and then hit my leg on something else and couldn't get up. I had to scream, and scream for my husband and he didn't hear me ... I ended up with a black eye and bruises all over my legs' (Louise)

As this account from the Royal College of Physicians 2008 audit of older people's experiences of falls and bone health services suggests, a fall can be a frightening experience for an older person, even when the physical injuries experienced are not serious.

Around 30% of older people aged 65 years and over living in the community experience a fall every year, and this rises to around 45% for people aged 80 and over. People with specific health challenges such as Parkinson's, visual impairment, stroke and learning disabilities also have an increased risk of falls.

Between 10-25% of older people who fall each year will sustain a serious injury, of which one of the most critical is a hip fracture. Osteoporosis is also implicated in fractures, and the annual cost to health and social care services resulting from fragility fractures is around £2 billion. Falls can have long term psychological impact, with enduring fear of falling being one example. Falls can also be a source of considerable anxiety for caregivers and families of older people, and are a major factor in admission to care homes.

Assessment for falls risk

The first principle underpinning effective falls prevention is a comprehensive assessment carried out with the older person at risk of, or having experienced a fall. Evidence suggests that older people do not always understand why falls occur. In our experience, a clear discussion exploring the rationale for the assessment and the older person's understanding about falls helps to ensure that the intervention process is person centred. The initial engagement with the older person at the point of assessment ensures that subsequent intervention is more meaningful, and should make it easier for the individual to assume an active role in falls prevention activities.

A comprehensive falls risk assessment may include the following:

Type of risk factor	Specific considerations
Personal	• History of falls • Gait, balance, mobility, muscle strength • Fear of falling and confidence not to fall • Vision • Cognition • Continence • Cardiovascular function • Medication • Osteoporosis
Environmental	• Use of home and outdoor space • Potential environmental hazards • Potential for reduction of risk through environmental adaptation
Activity related	• Habitual daily activities • Preferences for leisure activities • Ability and confidence (falls related self-efficacy) in carrying out activities • Potential for reduction of risk through adaptation/modification of the activity

A variety of assessments are available for use in determining risk of falls. Ideally, assessments should be standardised and person-centred, and recent NICE guidance[1] stresses the importance of involving appropriately qualified health professionals, such as occupational therapists, physiotherapists, nurses and physicians. Dedicated 'Falls Clinics', a requirement of the National Service Framework for Older People[2], provide specialist services for assessment and intervention in falls prevention.

What works in falls prevention?

The most recent overview of strategies to prevent falls amongst older people in the community is the Cochrane systematic review published in 2012.[3] This systematic review primarily examines the effectiveness of either exercise as a single intervention, or combinations of interventions such as exercise, education, medication review and home safety assessments and modifications.

Exercise

The programmes which are particularly effective in reducing falls are those which include balance and strength training exercises. The two most widely known programmes of this type are the Otago Exercise Programme (an individually tailored programme practiced at home and including walking[4]) and the Falls Management Exercise (FaME) programme (tailored group exercises also practiced at home). Other considerations with exercise are the intensity, frequency and duration of the programme (including practice). Graded exercise programmes (which are designed to get more difficult in response to improved capacity) appear to achieve the best results. Appropriately qualified exercise instructors are the best people to deliver these interventions.

Environment

Environmental assessment and modification or change, focusing on the home, also reduce falls. Typically, this involves an exploration of activity, use of space and potential hazards within the home by a healthcare professional and the older person, agreeing a plan of action, and either removing or modifying falls risks. The falls risk caused by visual impairment and the importance of appropriate lighting has been highlighted in new NICE guidance[5]. Home modifications seem to be more effective when delivered by a qualified occupational therapist. In contrast to a 'check list' type of approach to home safety, occupational therapists work together with older people to explore potential hazards and consider possible solutions, respecting people's views about which changes are meaningful and acceptable.

Combinations of interventions

Combinations of the above interventions tailored to the risk factors highlighted in the falls risk assessment are also effective in reducing falls. The most effective combinations include strength and balance exercises, home assessment and modification, with education and/or medication review. The way in which this type of package works is not yet fully understood, and more research is needed to unpack these complex interventions.

Challenges in falls prevention

One of the major challenges facing falls prevention services today is the implementation of research findings into everyday practice. A UK scoping exercise of falls clinics in 2007 found huge differences in the services offered, and because of this was unable to assess their cost benefit. National audits of falls and bone health services by the Royal College of Physicians[6] highlighted similar variation between services, and found a big gap between what organisations said they were doing, and what patient notes revealed was actually happening. In response to this, A Falls and Fractures Commissioning

Toolkit[7] has been produced for health and social care, and financial incentives are now in place to deliver effective services.

For older people at risk of falls, the motivation and support to engage with interventions such as exercise can be a difficulty, as with many younger people. Research based recommendations for improving older peoples' involvement with falls prevention include:

- public education;
- promoting falls prevention through emphasising immediate benefits (for example, improved confidence and increased independence);
- providing encouragement through a variety of avenues (such as health professionals, family and peers);
- matching interventions to older people's needs, preferences and capabilities;
- consideration and evaluation of methods to maintain engagement over the longer term.

Conclusions

Whilst we now know much more about what works in community falls prevention, obstacles still remain in terms of meeting the promise of large scale nationwide reductions in falls amongst older people. Current innovative research at the University of Southampton is exploring falls prevention with individuals with learning disabilities, with Parkinson's, and providing information about falls prevention in an accessible and relevant format. Future research should focus on better interagency working, consistent use of evidence based strategies and ways to support older people to engage in falls prevention, and maintain initial benefits over the longer term.

Additional resources

- Age UK Falls Prevention Guide (2013) Available at: http://www.ageuk.org.uk/health-wellbeing/keeping-fit/preventing-falls/
- AGS/BGS Clinical Practice Guideline: Prevention of Falls in Older Persons (2010) Available at: http://www.medcats.com/FALLS/frameset.htm
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[5]http://www.nice.org.uk/nicemedia/live/14181/64166/64166.pdf

[6]http://www.rcplondon.ac.uk/projects/national-audit-falls-and-bone-health-older-people

[7]http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/dh_103146

The programmes which are particularly effective in reducing falls are those which include balance and strength training exercises.

SPOTLIGHT ON: Assistive technology for people with dementia

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The main challenge for people with dementia is progressive and gradual damage to their cognitive abilities. Depending on the cause of their dementia, memory, concentration, language or planning and monitoring activities could be affected. As a result of these cognitive changes, people may experience difficulties managing their daily lives, looking after themselves, or maintaining relationships with the people around them. The demands on families and costs to services could be reduced by the timely introduction and widespread use of technology.

Currently available technology has the potential to support people who receive a dementia diagnosis by replacing or providing a way round the damaged cognitive processes. This can take the form of software or devices designed specifically to meet the needs of people with dementia or off-the-shelf items. For example, CIRCA (Computer Interactive Reminiscence and Conversation Aid) is a communication system developed to support people with dementia due to Alzheimer's disease (AD)[1]. It was designed specifically to address the memory problem that occurs in AD and take advantage of people's conversation skills that are not affected. CIRCA is intuitively designed to run on a touch screen and requires no mouse or keyboard. It has been extensively tested in the UK and abroad and can be used to support conversation in the home and a range of health and social care settings. It is particularly useful for getting to know someone and supporting relationships with caregivers[2].

In addition to specialist items such as CIRCA, many of the inbuilt functions of current off-the-shelf technology such as smart phones and tablet computers that everyone finds useful can benefit people with dementia. For example, digital calendars can help people to remember appointments and remind them when they are due. The COBALT (Challenging Obstacles and Barriers to Assistive Living Technology) project has been exploring the barriers to accessing new technologies with a wide range of people including those living with dementia. Brian is a 63-year old man with a mixed diagnosis of vascular and Lewy Body dementia. For the first two years after he was diagnosed, he lost his confidence in using technology including his home computer and mobile phone. Since September 2012, Brian has been blogging about his experiences of reacquainting himself with technology

on the COBALT project website[3]. He is now confident using his iPhone and many applications on his laptop and is becoming an experienced traveler and speaker, sharing his adventures with technology with audiences at home and abroad.

The biggest barrier to accessing technology for people living with dementia is a lack of awareness by people around them of how technology could help. Lack of insight into the specific needs of people with dementia, coupled with lack of imagination, means that currently available devices such as smart phones and touch screen computers are not being used to anywhere near their full capacity to support people like Brian. There has also been a lack of investment in developing tailored and purpose-built items such as CIRCA.

The evidence suggests that a dementia diagnosis excessively disables people by lowering the expectations of the people around them. This leads to a rush to take things away from people with dementia, to do things for them and reduce demands on them[4]. **In reality, assisting people to keep doing things for themselves for as long as possible would actually be much more beneficial for them and would delay the demand for care from families or health and social services, thereby saving money, reducing stress and improving quality of life**.

[1]http://www.circaconnect.co.uk

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[3]http://cobaltproject.org

[4]Astell, A. J. (2006). Personhood and technology in dementia. *Quality in Ageing*, 7(1), 15–25.

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Cognitive Stimulation Therapy (CST) for people with dementia

Key messages

For people with dementia, Cognitive Stimulation Therapy (CST) has been shown to significantly improve cognition and quality of life. Longer term trials show that these benefits continue over time.

Research shows that CST is cost-effective and might be as effective as some anti-dementia drugs.

Clinical CST programmes are time limited, but this creates a loss for people being treated. CST programmes should be ongoing and offered in the community and also for care home residents.

What is CST?

Cognitive Stimulation Therapy (CST) is an evidence-based, group therapy, developed and evaluated in the late 1990s. At this time, there was extensive anecdotal evidence that a range of non-pharmacological, or 'psychosocial', therapies had benefits for people with dementia, yet very little understanding as to which therapies were the most effective and how to use them in practice. Additionally, psychosocial research did not adhere to the same standards and quality controls as those of dementia drug trials. As a result, those making decisions as to how to allocate resources for the treatment of dementia were focusing on medical interventions, despite the fact that their effectiveness was sometimes limited.

Our aim was to develop a new, group intervention which incorporated the 'best bits' of existing therapies, also building on our knowledge of maximising learning and potential in people with dementia.

We began by systematically reviewing all the evidence for a wide range of psychosocial interventions for dementia, and identifying the most effective features of each. These were integrated into a 14-session group programme that was later named CST.

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It aims to improve cognitive skills and quality of life for people with dementia through themed activities including faces, food, word association, categorisation and discussion of current affairs. The 'key principles' of CST include stimulation of language and executive functioning, encouraging implicit learning, the continual development of new ideas and associations and a focus on opinions rather than facts.

The evidence base

In our initial research trial[1], 201 participants were randomised to receive CST over 7 weeks, compared to a 'treatment as usual' control group. There were significant improvements in cognition and quality of life following CST, with cognitive benefits similar to those found using anti-dementia drugs. An economic analysis through partners at the London School of Economics showed CST to be cost-effective[2]. A subsequent trial of longer-term CST at University College London (UCL) showed that quality of life continues to significantly improve over a 6 month period using weekly CST sessions following from the initial programme[3]. Subsequent analysis of the trial data showed that CST benefits memory, language and executive functioning in dementia, with the most marked impact on language[4]. A study using complex neuropsychological tests showed significant changes in verbal memory, non-verbal memory,

language comprehension and orientation following CST[5]. Qualitative interviews with service users and staff showed that changes generalised into everyday life, e.g. improvements in mood and concentration[6]. A recent Cochrane systematic review has confirmed the effectiveness of a range of cognitive stimulation approaches[7].

CST in the UK and beyond

In 2006, the government's National Institute for Health and Care Excellent (NICE) guidelines recommended that people with mild to moderate dementia of all types should participate in group Cognitive Stimulation, regardless of medication prescribed. This was the only non-drug intervention recommended to treat cognitive symptoms of dementia. More recently, the World Alzheimer's Report[8], stated that CST should routinely be given to people with early stage dementia. These guidelines, along with the continued research evidence, appear to have led to the widespread use of CST in the UK and beyond. The National Audit Office[9] reported that CST is used by 29% of community mental health teams, a figure predicted to have increased considerably. Recent data from the Memory Services National Accreditation Programme and Memory Clinics Audit suggests that 66% of UK memory services provide CST. The CST manual has been translated into several languages including Japanese, Spanish, Italian, German, Portuguese and Swahili. CST is being used worldwide, for example in Australia, America, South Africa, New Zealand, Germany, Canada, Chile, Italy, Japan, Nepal, the Philippines and Portugal.

How can CST be implemented?

CST was designed to be a simple intervention which could, in theory, be delivered by anyone working with people with dementia following a manual. However, skills and confidence in offering therapeutic group interventions for people with dementia, as well as supervision and management support, are essential. We have now published three manuals, two in the UK, describing the CST and longer-term 'maintenance CST' programmes[10 11], and one in the US[12 13]. NICE recommend that Cognitive Stimulation should be offered with 'training and supervision'. Following this recommendation, a one-day CST training course was developed, which broadens peoples' skills in offering CST according to its guiding principles and encourages people to develop new techniques through experiential learning.

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Problems and limitations

Many people cannot access groups, due to geographical isolation, transport problems or physical health problems. Further, some people do not enjoy or benefit from group activities and prefer individualised interventions. At UCL, we have developed a one-to-one CST manual, known as 'iCST / individualised CST'. It is currently being evaluated as a large clinical trial, led by Professor Martin Orrell and supported by the NIHR Health Technology Assessment programme. The results will reveal the effectiveness of CST when delivered by informal caregivers or care professionals in a home setting.

There is strong evidence that CST is offered by many NHS trusts. However, there is limited evidence of its use in care homes. Ironically, the original research was primarily conducted in care homes for people with moderate dementia, yet this seems to be the most neglected group in terms of being given evidence-based therapies.

A common clinical dilemma surrounds the question of what to do once the programme is over. Many clinicians report wider social benefits for their clients and find that the ending of CST sessions can be experienced as a great loss. CST was designed as a time-limited programme because it was part of a clinical trial where there were limits in resources. Yet in a natural setting, it is not necessarily in a person's interests to stop a therapy while it continues to provide benefits, in the same way that medication would rarely stop while it was shown to be working.

Are there ways for CST to be offered on a longer-term basis within the community? Allocation of further resources and wider implementation need to be on the agenda for decision makers, as there are limits to what the NHS can currently offer. There are economic arguments for the longer term implementation of CST. The NHS Institute for Innovation and Improvement[14] conducted an economic analysis of alternatives to antipsychotic drugs for individuals living with dementia, focusing on the cost and benefits of providing CST. They concluded that combining health care cost savings and quality of life improvements, behavioural interventions generate a net benefit of nearly £54.9 million a year to the NHS.

See www.cstdementia.com for further information and references.

They concluded that combining health care cost savings and quality of life improvements, behavioural interventions generate a net benefit of nearly £54.9 million a year to the NHS.

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[14]NHS Institute for Innovation and Improvement. (2011) An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia. The NHS Institute for Innovation and Improvement, Coventry House, University of Warwick Campus, Coventry, UK.

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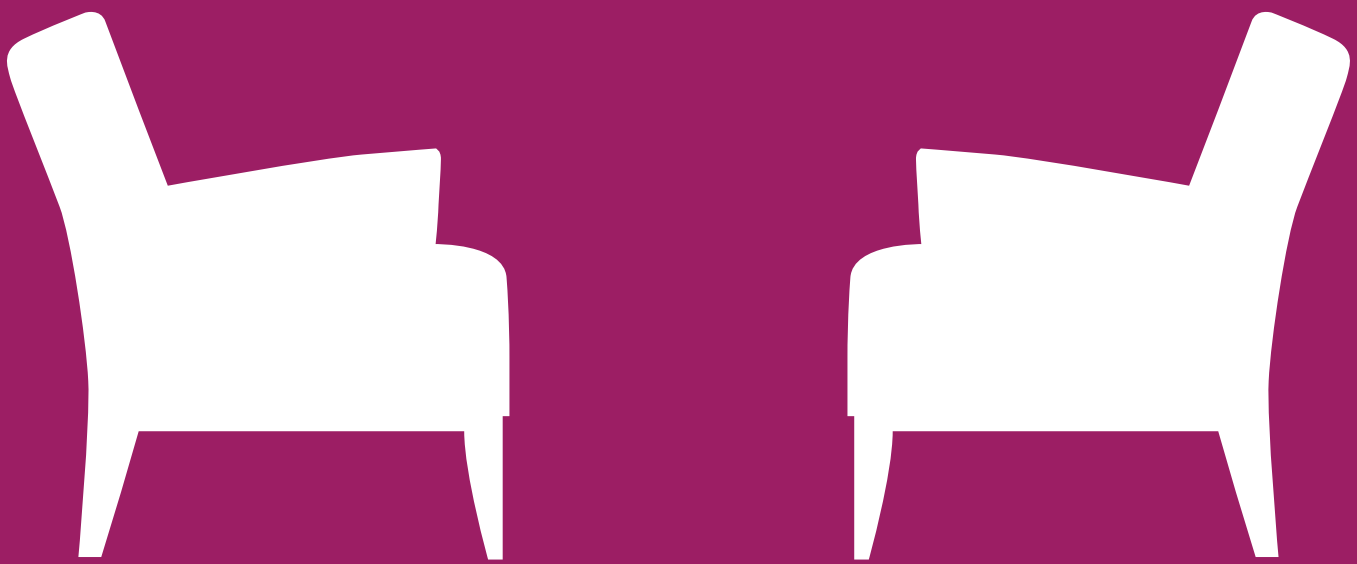

SPOTLIGHT ON: Memory services for people with dementia

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As the population is growing older this is accompanied by an increase in number of people with dementia, but there is still stigma in relation to dementia. Despite improvements in the diagnosis rates recently, it is likely that around half the people with dementia still remain undiagnosed.

Memory services commonly offer assessment and diagnosis, access to drug treatments and psychological interventions, information and support as well as providing a place for research. Most memory services in the UK now have access to Cognitive Stimulation Therapy which has been shown to help cognition and quality of life for people with mild to moderate dementia.

Across the country many memory services have developed without the availability of a consistent national model. Sometimes services have been put together from enthusiastic clinical staff; other services may have developed initially funded by research studies aiming to find useful drug treatments for people with dementia.

In 2007 a scoping exercise funded by the Health Care Commission identified that there was a need for a set of quality standards for memory services to provide a national model of best practice and help services which were keen to improve to reach a recognised level of quality. The standards were developed through a review of the literature together with a wide consultation process.

Providing access to timely diagnosis for people with dementia is a very important start to their care. The UK leads the world in providing the first national system for quality improvement in memory services, and the Prime Minister's Challenge on Dementia has encouraged more services to sign up, so that there are now 73 across England and Wales, the Isle of Man and the Isle of Jersey. Many people with memory problems and their families will now have access to top quality memory services in their area which have been accredited by the Memory Services National Accreditation programme (MSNAP).

The standards cover a comprehensive range of areas intended to ensure that services are thoroughly evaluated. The information collected includes questionnaires for patients and carers about their experiences, a questionnaire to the staff about the local resources, supervision and training, a checklist about policies and procedures, a questionnaire to local referrers such as GPs gathering their views on the service, an organisational checklist looking at policies and procedures and lastly a screening of case notes to see whether vital information has been properly recorded, including details on consent, assessment and investigations, as well as information about the diagnosis.

A recent report on 298 carers and 280 people with dementia about their experiences of attending memory services showed that they were very satisfied with the process of diagnosis and felt they were being treated well and with courtesy. However there was a lack of written information across a range of key areas. More recently we looked at services which have been assessed for a second time and found that they are continuing to improve. Patients, carers and memory services staff have given a lot of positive feedback about the MSNAP quality improvement process. The MSNAP website provides a map and list of services who are members, accredited services and those accredited with excellence.

http://www.rcpsych.ac.uk/quality/qualityandaccreditation/memoryservices/memoryservicesaccreditation.aspx

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