



Care Home Whispers

Listening to the Voices of Older People
living in Gloucestershire Care Homes
February 2015

ImogenBlood
& Associates

 Innovations
in Dementia



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Foreword

Older but not overlooked – Older people need to feel and remain an active part of our communities whether they live in their own homes or residential care. Both should be part of the police beat with the local officer being visible and proactive with all vulnerable groups.

Police and Crime Plan priority 2012-16

It was not by accident that I wanted a sharper focus on the older and more vulnerable members of our communities during my four years as Police and Crime Commissioner. What seems to be a growing number of cases where care home residents have been subjected to the most brutal and inhumane treatment illustrates the need for vigilance. That none has been in our county is a cause for thanks but not complacency.

The media reports them as scandals, but should we be surprised when the evidence in these cases points to depositories whose excesses have been ignored or overlooked by the outside world, often over a long period of time? Of course, we like to think our care homes exhibit the highest standards of compassion. I believe the vast majority of carers in our county do great work, often in very difficult and distressing circumstances. Some are family members; others are dedicated professionals who deserve our gratitude and admiration. My aim is to ensure that is the case throughout Gloucestershire and where there are faults they do not go unnoticed.

Even so, one of the underlying truths of this report is that many people are scared stiff at the prospect of 'ending-up' in a care home. They see them as places where you go to die, rather than to live, and most assume they will be bleak and depressing. While those media reports of institutional abuse and neglect have acted as a sharp and much-needed wake-up call they have also contributed to feelings of guilt, fear, suspicion and blame.

There are many questions to be asked around the performance of care homes. It is important that residents feel they have a voice; that they can use it and it is heard. Then we can truly say they may be older but they are certainly not overlooked.

I would like to thank Age UK Gloucestershire, Gloucestershire Care Providers Association, the team at Imogen Blood Associates and everyone else who has worked on The Care Home Whispers Project. Getting a first-hand account from residents about their lives, what matters to them and what makes them feel safe is the first part of providing what they expect of a good life in care.

Martin Surl
Police and Crime Commissioner for Gloucestershire



Foreword

Older people living in residential care and nursing homes are a group within our communities whose 'voice' is rarely heard. Other than people who have close links with individual residents or a care home facility, most of the wider community have no real way of knowing what older care home residents think and feel about the environment in which they living, or indeed many of the same things relating to quality of life that matter to all of us.

This project set out to find a way to make that 'voice' heard. With financial support from the Gloucestershire Police and Crime Commissioner and in partnership with GCPA (Gloucestershire Care Providers Association), the GSAB (Gloucestershire Safeguarding Adults Board), GCSNHST (Gloucestershire Care Services National Health Service Trust) and Age UK, we commissioned Imogen Blood Associates and Innovations in Dementia to consult with a wide range of care and nursing home residents in Gloucestershire, as well as listening to the views of staff and relatives.

To our knowledge, this is the first consultation of its kind in Gloucestershire. We are very grateful to the homes, staff, families and of course the residents themselves, for their willingness to share their experiences and contribute to this process. It has been heartening to learn that despite the occasional horror story in the media, there are many examples of good practice within Gloucestershire Care Homes, and that the majority of residents we spoke to feel safe and secure.

The consultation does, however, raise a number of areas where the quality of life of many care and nursing home residents in Gloucestershire could be improved and enhanced; in particular, a more 'asset based' approach, which takes account of the contribution individuals can make rather than simply focusing upon their support needs, greater use of technology and perhaps most importantly, an increased sense of choice and control.

Some of our most vulnerable citizens live in care and nursing homes: as a civilised society we need therefore to listen to what they are saying and do what we can to ensure their quality of life is optimised. I sincerely hope that the 'voice' heard in this document is listened to by professionals and the wider community alike.

Christina Snell
Chief Executive Officer
Age UK Gloucestershire

“A lot of people outside don't want to know what's going on in care homes. It's like 'I'm alright, Jack!'”

Until relatively recently, few policy makers and external agencies had thought to go into care homes and find out about the lived experience of the older people living in them. In Katz et al (2011), we identified several explanations for this:

Older disabled people are generally still viewed through the medical, rather than the social model of disability (Blood & Bamford 2010). The barriers they face as a result of their impairments are seen as insurmountable ('what can you expect at this age?') and the discourse is one of dependence, care, dignity, frailty and pity. Viewed as passive recipients – rather than active consumers – of care, the focus has been on their needs in relation to services, rather than their strengths or their broader aspirations in relation to their lives.

Gordon et al (2014) found that 75% of care home residents had significant cognitive impairment, with 62% having a diagnosis of dementia. This presents a number of challenges: can people with dementia consent to be involved in consultation and can we take what they tell us as reliable? These practical dilemmas have reflected a general societal attitude that regards people with dementia as having little to contribute. The acknowledgement that people with cognitive impairments could and should participate in decisions about their care and lifestyles has been relatively recent (e.g. Feinberg and Whitlatch 2001; Trigg, et al 2007, Williamson, 2012).

Older people – especially those living in care homes – tend to be seen as a homogenous group: it is as though all our diversity converges into a handful of stereotypes as we enter this stage of our lives. Older people with high care and support needs are seen as other: their humanity and individuality overshadowed by their health conditions and by their status as a care home resident. As Scourfield (2007) argues,

“It is often assumed that when someone enters residential care, their disability or illness is so all-consuming that they have no interest in anything other than their personal care and their day-to-day comfort” (p.1136)

Finally, as the quote from one of our participants at the top of this page suggests, many people are scared stiff by the very prospect of care homes. Seen by many as places where you go to die, rather than to live, most assume they will be bleak and depressing. Media reports of institutional abuse and neglect have acted as a sharp and much-needed wake-up call for independent people to go in and hear the voices of care home residents. However, they have also left a wake of guilt, fear, suspicion and blame around the sector. Many more questions have been asked about the performance of individual care homes but those of us outside of care homes have taken little responsibility for issues which are often systemic.

**As John Kennedy of the
Joseph Rowntree Foundation
recently asked:**

“When did care homes become absolutely totally responsible for the complete physical, mental and emotional wellbeing of those in their care? When did everyone else opt out? (Kennedy (2014), p.38)

The Care Home Whispers Project sought to start redressing some of this by going into care homes in Gloucestershire and hearing from residents about their lives, what matters to them, what makes them feel safe and what they think makes a good life in care. We did not do this to inspect or judge the individual homes themselves (as Care Quality Commission, 2014), though inevitably we have drawn some general (but anonymised) comparisons between them in our

reflections. We were keen, instead (like the My Home Life project (Owen & Meyer, 2012) to identify and share local good practice in the sector. We were also keen to start the conversation about what the wider community in Gloucestershire – the voluntary sector, the health and social care sector, the Police and the general public – can do to improve the quality of life of people living in care homes and open the window on these relatively unheard voices?

Our findings build on a growing evidence base about the views and experiences of older care home residents, including people with dementia. Bowers et al (2009) identified the ‘Keys to a Good Life’ in care, through involvement of older residents. Williamson (2010) included residents from several care homes in his discussions about quality of life indicators. Whilst we were starting the fieldwork for this project, the Older People’s Commissioner for Wales (2014) published her review of care homes, which involved discussions with residents in a hundred homes. Although a detailed literature review was beyond the scope of our study, we have referred to the findings of these and other studies where we feel they support or contrast with the themes which emerged from ours.

“I’m glad they’re listening to people like us. When you hear about how they treat older people in some homes...”

**The project’s
objectives were to:**

- ▶ Enable older people living in Gloucestershire care and nursing homes to express their views about things that matter and are of concern to them, including their level of access to the police;
- ▶ Report back on what is important to older residents of care and nursing homes in the county, particularly in relation to staying and feeling safe and secure, but also wider wellbeing issues;
- ▶ Identify good practice that can be shared with other providers and professionals; and
- ▶ Inform the review/ development of Gloucestershire County Council Quality Assurance Framework for residential services for older people.

**Aims
And
Objectives**

We were asked to engage with older people living in a range of residential and nursing care homes in the County, including large and small, rural and city-based homes and homes reflecting a mix of socio-economic groups. Our target was to make sure that at least a third of our participants were “people most at risk of being overlooked due to barriers to communication, such as sensory loss and dementia, or who have no external contacts and therefore no-one to advocate on their behalf”. We were also asked to explore any particular issues for diverse groups within the sample.

Steering Group and Project Team

A Steering Group oversaw the project, meeting at the outset and to review the first draft of the report. This consisted of:

Christina Snell, CEO Age UK Gloucestershire

Riki Moody, Business Manager, Gloucester Care Providers Association (GCPA)

Ann Gribble, Safeguarding Adults Board Project & Business Officer

Sarah Warne, Named Nurse Safeguarding Adults / Clinical Quality Manager

Hayley Clemens, Communications at Safeguarding Adults Board

Imogen Blood & Associates Ltd, in partnership with Innovations in Dementia, was commissioned to undertake the work.

Imogen Blood & Associates (IBA) is an independent research consultancy with particular expertise in older people's housing, care and support and in equality and diversity. We are passionate about using research to develop better and fairer ways of doing things and making sure that diverse (and often unheard) voices are at the heart of this process. We have considerable experience of designing and delivering engagement and qualitative research projects with older people with high support needs. We have published a number of reports on dementia, quality of life, and best practice in housing and care for Joseph Rowntree Foundation, the Barnwood Trust and Research in Practice for Adults.

Innovations in Dementia (IID) is a Community Interest Company, which works in a positive way with people with dementia, demonstrating to others what they are capable of with the right approach, support and opportunities. We run innovative projects which include: involving people with dementia and hearing their voices; people with dementia being part of their communities; developing accessible information; and enabling people with dementia to make the most of technology and the internet. We have conducted many consultations of people with dementia, including for SCIE (the Social Care Institute for Excellence) and the Department of Health. We have previous experience of conducting engagement projects in care homes and are currently running the national DEEP programme on behalf of the Joseph Rowntree Foundation, to develop the collective voices of people with dementia.

The Project Team consisted of:

- ▶ Imogen Blood (IBA) – Project Lead, Design, Fieldwork, Analysis and Report Writing
- ▶ Rachael Litherland (IID) – Design, Fieldwork, Analysis and Report Writing
- ▶ Jenny Pannell (IBA) – Care home recruitment, Fieldwork
- ▶ Alise Kirtley (IID) - Fieldwork
- ▶ Shelly Dulson (IBA) – Data analysis, Business Support

Acknowledgements

We would like to thank the Police and Crime Commissioner for providing the funding which made this project possible. We would like to thank those at Age UK Gloucestershire and Gloucestershire Care Providers' Association who promoted the project and put us in touch with care home providers. We would like to thank all the steering group members for your support and feedback.

We would like to thank Alzheimer's Society Gloucestershire and the members of one of their support groups who shared their views and experiences with us.

We are very grateful to those care home managers who had the vision and trust to let us into their care homes; and the staff who made us welcome, introduced us to residents and fed us!

Most of all, we would like to thank the older people who agreed to speak to us about their experiences of living in care, many of whom opened up and shared some very personal and, at times, painful emotions. We hope that this report will amplify your voices and educate and inspire those who hear them.

Methods



Chapter 01 Methods

Recruiting homes

The steering group and project team worked hard to recruit as diverse a sample of care homes as possible to participate in the study, including residents with dementia and other high support needs. Our approaches included:

- ▶ Producing a two page information sheet for care home managers explaining the project and what participating in it would mean for them, their staff and residents;
- ▶ Producing a one-page flyer summarising the project's aims in plain English, setting out the core questions in speech bubbles and showing photographs of the engagement team;
- ▶ One of the members of the GCPA Board kindly arranging the pilot visit to test out the project material;

A presentation at the GCPA care homes sub-group meeting on 5th November 2014, which generated half a dozen volunteer homes;

- ▶ Emailing the 17 non-GCPA member homes from the Gloucestershire Care & Support Services Directory 2014/5 which have a publicly available email address and inviting them to participate: this did not generate any response; and
- ▶ Direct approaches to personal and professional contacts of Age UK Gloucestershire and the engagement team, which generated five volunteer homes.

Recruitment of care homes to the study took much longer than we had anticipated. Unfortunately, we were not able to include any large homes (40 or more beds) in the study and only two homes out of our resulting sample were outside of the towns of Gloucester and Cheltenham. Otherwise, we feel that we succeeded in recruiting an interesting mix of establishments.

The sample of care homes

We visited 12 homes, including our pilot site. The table overleaf sets out the characteristics of the sample:



Location:

Characteristic	Number of homes in sample
Gloucester	6
Cheltenham	4
Stroud	1
Cotswolds & Cirencester	1
Urban/ suburban	9
Rural/ semi-rural	3



Type of home:

Residential	10
Nursing	2
Older people only	11
Mixed age (Learning Disability)	1



Number of beds:

10 beds	1
10-19 beds	1
20-29 beds	6
30-39 beds	4



Provider type:

Small private (1 or 2 homes)	6
Medium private (3 – 10 homes)	2
Charity	4
GCPA member	9
Non-GCPA member	3

We asked each care home to tell its residents about our visit in advance. We supplied flyers to assist in this, with the date of our visit included. Most homes distributed these to individuals and/or displayed them on notice boards. In some of the larger homes, a member of staff had identified a number of volunteers for us in advance. We used a mixture of approaches whilst on site, including:

- ▶ Asking a member of staff to introduce us to people who had volunteered in advance or to introduce us to people who might want to participate (this was particularly useful for residents who were staying in their rooms that day);
- ▶ Spending time in lounge areas, speaking informally to people on their own or in pairs or small groups;
- ▶ Eating lunch with the residents, which gave us the opportunity to get to know people informally (sometimes this led into a more formal interview after lunch); and
- ▶ Ensuring that residents with dementia were identified as potential participants.

It was important that views from residents with dementia were included in the engagement study, including people with more advanced dementia. To ensure people with dementia were consenting to being involved in the consultation, we applied a rigorous consent process for all residents. This included:

- ▶ Making positive eye contact with residents in order to make an initial approach;
- ▶ Providing enough information about the engagement project and its anticipated outcomes, to assist people in making a considered decision about participation. A written document about the project was shared with each resident (see Appendices) and this was used as a prompt for a verbal discussion;
- ▶ We developed a simple consent form (also included in the Appendices), setting out people's rights in the consultation process in large print plain English - we used this flexibly, either as a prompt for us or as a form to work through with participants;
- ▶ We explained how people's comments would be used and reported and that their names and identifying features would not be included in final reports;
- ▶ People were told they did not have to speak to us, and were asked to confirm that they were happy to continue. Verbal consent (or lack of consent) was taken; others indicated consent non-verbally e.g. the nod of a head or the wave of a hand i.e. to go away;
- ▶ People were asked at intervals if they were happy to continue with the interview. Some interviews were quite lengthy, and people were asked if they were happy to proceed. In other situations, non-verbal communication suggested that people were not happy to carry on with the interview and this was checked back with the participant; and
- ▶ We visibly reinforced our role by explicitly writing notes or tape recording conversations. This allowed residents to continue to give (or withdraw) consent by asking what we were doing and why.

We developed a Safeguarding Protocol at the outset of the project, in conjunction with Age UK Gloucestershire and the safeguarding leads on the steering group. This set out our responsibilities and actions in the event of any safeguarding concerns.

We produced a short demographic form and, where we had gathered a significant amount of data from people, we completed this form with them, stressing our approach to confidentiality. Sometimes participants gave their permission for us to ask the manager for this information, especially when they found it difficult to remember.

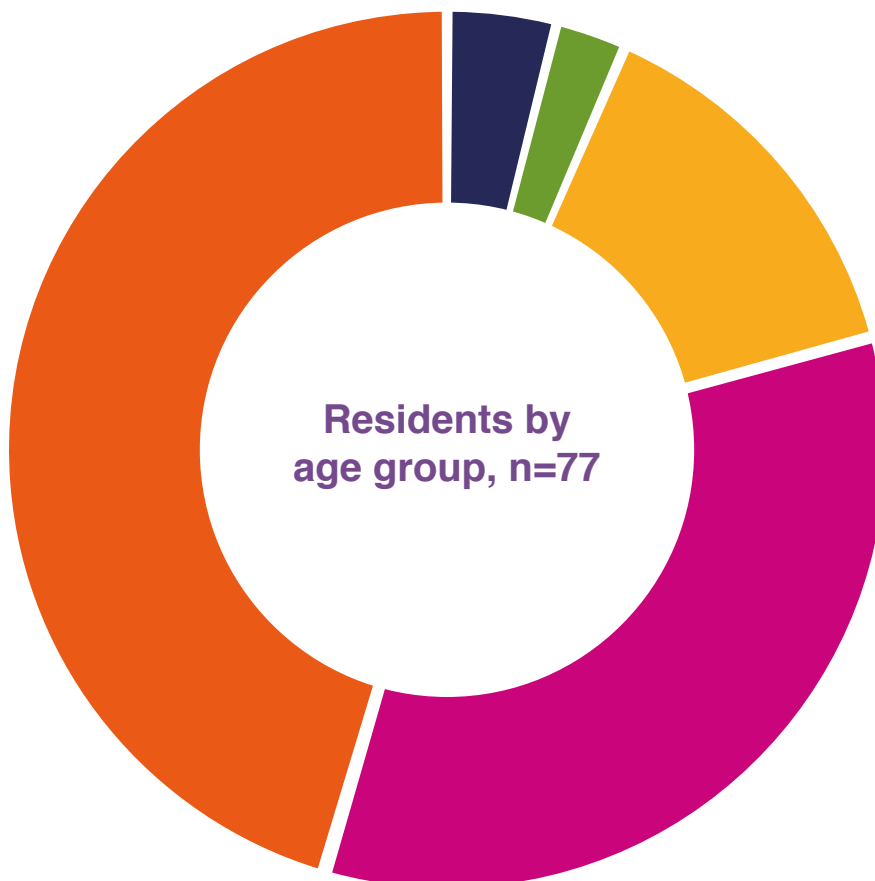
We took basic demographic details from the 88 people with whom we had a substantial conversation. Many more were involved to a lesser degree: in short informal conversations, through sitting on lunch tables with us, through observation, through being in the lounge whilst a group discussion was being held and perhaps making the occasional comment. We did not attempt to collect demographic data from these other people.

Gender

Women significantly outnumbered men in almost all of the homes we visited. We worked hard to ensure that we spoke to as many men as possible. Of our 88, 17 (19%) were men. 2011 census data (Office for National Statistics, 2014) suggests that 19% of care home residents aged over 85 (and 25% of those over 65) in the South West of England are men, so our sample seems to be broadly representative.

Age group

The pie chart below shows the age groups of those 77 of the sample for whom we had accurate age data. This demonstrates the advanced seniority of our sample, nearly half of whom were in their nineties, or beyond. Those aged 70 and under were all residents of the Learning Disability home.



Ethnicity

We deliberately targeted care homes in central Gloucester in the hope that this would maximise our chances of speaking to some care home residents from black and ethnic minority (BME) backgrounds. However, we did not encounter any BME residents at any of the homes we visited and all but three of the sample identified themselves as 'White British/ English', with the remainder originating from other parts of the UK or Europe.

Bowes et al (2011) recently conducted qualitative research with 37 BME care home residents across the UK, though they reported that recruitment was challenging and they focused their efforts on large cities with significant ageing BME communities.

A total of 38 residents (43% of our sample) were classified (by us, based on how they presented on the day) as having a significant degree of cognitive impairment.

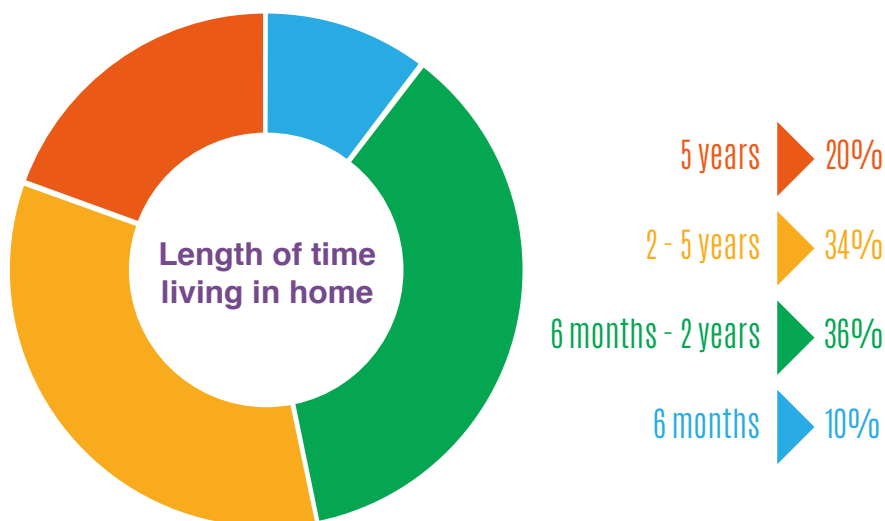
13 of those with a significant degree of cognitive impairment also had a severe sensory impairment and/or severe mobility issues.

Up to 12 people may have had more advanced dementia. At the time of our visits, they found it very difficult to engage. However, we did succeed in getting limited engagement and some feedback by using photographs and emoticons.

Out of those who did not present as having a significant degree of cognitive impairment (over and above occasional forgetfulness that might be typical of their age), 5 had significant sensory loss, 6 had a learning disability, 14 had restricted mobility (needing support and/or a walking frame/ wheelchair to move around) and a further 12 had multiple conditions (including severely restricted mobility, sensory loss, mental health but not dementia).

Two-thirds of our participants had lived very locally to the home before moving in, either in the same small town/ part of a larger town or the surrounding rural area. 24 (29%) had moved from another part of Gloucestershire and only 5 (6%) had moved from further afield.

We were struck by how many of our participants had been living in the care home for a long period: the majority (54%) had been there for more than 2 years, but we also met a significant number of people who had been living in their home for a decade or more. Some of the older people with Learning Disability had spent most, if not all, of their lives in some form of care institution.



As the following table shows, the majority of our participants had a relative living reasonably close by who visits regularly (though this varied considerably from receiving visits virtually every day to perhaps visits once or twice a month). Many did not enjoy that level of contact and a handful of participants did not have any close relatives at all.

Contact with relative	No. of Residents	% of Residents
A relative nearby who visits regularly	54	70%
A relative who is in contact by phone/ visits occasionally	16	21%
No close relatives	7	9%

Where the opportunity arose, we also had short interviews/ conversations with care home staff, visiting relatives and volunteers. In total, we spoke to:

- ▶ 8 Managers
- ▶ 12 carers and other staff (e.g. Activity Coordinators)
- ▶ 6 visiting relatives/ friends
- ▶ 3 volunteers/ visiting older people

We held a focus group discussion with a further 6 relatives of people with a diagnosis of dementia living in Gloucestershire care homes, through a support group at Alzheimer's Society Gloucestershire and conducted one phone interview with a relative.

We presented and discussed our findings with participating care homes at an interactive forum hosted by the Gloucestershire Care Home Providers' Association on 27th February 2015. Only 5 managers, representing 4 of the participating homes, attended this event but they engaged in a lively and positive discussion about the report's findings and possible next steps.

We developed six broad questions to guide our conversations with residents (our full topic guide is included in the appendices):

- ▶ Who do you see regularly?
- ▶ How do you keep in touch with the outside world?
- ▶ Do you get out of the home much?
- ▶ What sort of things do you like to do?
- ▶ What's it like living here - do you feel happy, safe and secure?
- ▶ Do you have a say in how the home is run?

Given the huge variation in the cognitive and communication abilities of our participants and the types of conversations we had with them (ranging from a quick chat as part of a group over lunch to in-depth one-to-one interviews in a private setting), we did not ask all these questions of everyone we spoke to. We allowed conversations to develop as naturally as possible, prompting to tease out views and experiences which specifically related to our engagement questions.

We also developed a range of 'tools' to guide our discussions with residents, especially those who have dementia, learning disability or other communication issues. In practice, we used these quite flexibly, depending on the communication needs of the resident and the setting for the discussion. These included:

- ▶ A pack of photos which we compiled to illustrate different types of activities (from painting to animals, and from country walks to abseiling) and different people who might be seen regularly in the home (children and young people, the doctor, the vicar, the Police). We used these where people found it difficult to respond to direct questions (certainly at the outset of the interview, though some 'warmed up' after this initial activity) and to prompt them to talk about things they enjoyed doing, where they found this difficult to remember and/or articulate;
- ▶ A 'feelings sheet' consisting of half a dozen emoticons (faces showing different emotions) to which people with limited communication could point;

This approach was based on user led recommendations by people with dementia which identify the need for written information to be presented in a way that is clear, easy to understand, is not too wordy, presents ideas concretely (rather than abstractly), presents information in manageable chunks, and is reinforced with pictures and illustrations that are accessible and not likely to be misinterpreted (DEEP 2014).

We recorded our conversations with residents, either by audio recording or by taking handwritten notes. Fieldworkers then typed up their own notes from these sources in a Word document, giving each participant for whom we had collected demographic data an identifier (consisting of the fieldworker's initials and a number). These same identifiers were also used on the demographic forms so that qualitative and quantitative data could be linked (anonymously) for each participant. Demographic data was entered into an Excel spreadsheet.

IBA has an Information Security and Confidentiality Policy, which sets out our approach to collecting, storing and processing data in accordance with the Data Protection Act. We are registered with the Information Commissioner's Office.

We 'coded' the data (i.e. sorted it by theme), using qualitative data analysis software (QDA Miner). This enabled us to pull together all the comments which, for example, included people talking about feeling safe or unsafe, and compare them to each other. Imogen then read through all of the write-ups separately, to ensure that we had not missed anything by drawing comments out of the context of our discussions with individuals. Rachael also read through all the write-ups to focus on interpreting some of the more ambiguous or metaphorical comments made by people with more advanced dementia.

There were a number of reflections and learning points arising from our methodology:

- ▶ The difficulty of persuading homes to participate – recruitment of homes took much longer than anticipated and it was much harder to build a diverse sample than we had hoped. This is perhaps unsurprising, given the level of scrutiny the care home sector has faced in recent years (Kennedy 2014, Owen & Meyer 2012). Other similar studies (e.g. Bowers et al 2009; Bowes et al 2011) have experienced issues with the recruitment of homes.
- ▶ Recognising that our sample (of homes) may well have been skewed towards the better homes in the county, since those who felt they had something to hide or did not see the merit in someone external engaging with their residents would probably not have volunteered. Where engagement projects have had the mandate to randomly sample and turn up at homes unannounced (e.g. Older People's Commissioner for Wales, 2014), the overall picture of life in homes has been, on balance, much bleaker.
- ▶ We were conscious of the risk that managers might steer us towards residents who would paint the best picture of life in the home and sought to balance this by speaking more casually and spontaneously with residents at lunch and in the communal areas. We generally got a mixed picture from those to whom managers introduced us: we did not get the sense that these had been 'cherry-picked'; most homes gave us free access to circulate and to make independent connections with interested residents.

- ▶ There were limits to our consent process in a small number of situations where the very act of drawing attention to the consent paperwork seemed to provoke anxiety for some residents with more advanced dementia. Some of this group seemed happy and content to hold conversations or to make a connection with the interviewer but the act of working through an explicit consent process caused an amount of stress and confusion. In these situations, we ignored the more formal consent process, and continued the conversations based on the clear enjoyment that these residents were gaining from the engagement encounter.
- ▶ The vast majority of participants seemed to enjoy participating in the project. A number told us that they had appreciated the opportunity to speak to someone from outside the home in this way. A few made comments about how easy and pleasant it was to speak to members of the engagement team and some told us they were glad that this piece of work was happening.

Responses given
by people with
dementia

Realities and accuracy of responses

Many residents with dementia expressed views and perspectives that are unlikely to be accurate - for example, referring to parents who are still alive back home, or describing the care home as their work environment. For example, when we asked one resident about her experiences of living in the care home, she looked around the dining room and talked about the village and how she lives in the village and what a great village it is – “there is lots going on and everyone looks after each other – I used to help out but I can’t anymore.”

Limitations in terms of time available for the project meant that it was very difficult to assess for accuracy the factual content of people’s commentaries, or to explore or fully interpret the metaphors and emotions behind the words that people with dementia were using. However, the feelings or emotions expressed alongside the words provide a window on people’s story of the past and how this interplays now with their day to day experiences within the care home. In the example of the woman above, we got a sense of mutual support between other residents; of past (and maybe present?) connection with the local area; and of a sense of loss about the personal ability to make a contribution. Caution has been exercised when extrapolating from people’s stories in these situations, but the feelings and emotions expressed by residents feature strongly in our reporting.

None of our consultation questions made reference to the condition of dementia and yet, many residents, unprompted, talked about dementia in their responses.

For some there was a fear:

“ I don't think that people with physical disabilities should be in the same category as people with dementia. I don't agree with it because as you get older, you are vulnerable.....[in what way?] to self-doubt, you start to question your own memory – which isn't as good as it used to be – and you start to wonder whether you are getting dementia too but you feel silly to ask... and this just creates worry. ”

Some residents (who clearly did have significant memory loss) were keen to distance themselves from the label of 'dementia'. One person told us:

“ I can talk and walk – I'm not ... ”

[tapping her head to imply that she doesn't have dementia, though staff confirmed that she does].
Another said:

“ The doctors did tell me what this problem with my short term memory is [is it dementia?] Oh no I'm not doo lally – but it's something to do with my short term memory – but I've forgotten! And now I never see a Doctor anymore – well not that I know of. ”

Some residents were aware of their own diagnosis of dementia or Alzheimer's Disease and felt it was important to raise awareness about what it is like to live with this condition:

“ A lot of people are frightened of people like us, who have lost our marbles. But we get on - once we have come to terms with it [dementia], you have to push on, instruct our own families ”

As early diagnosis and public awareness regarding dementia improve, we would expect in future to see not only more people with dementia in care homes but also more of this group who have an awareness of their diagnosis and insight into their condition. Staff teams will need to support people to remain or become connected (perhaps to groups outside of the home, including perhaps, peer support groups), whilst continuing to managing the fears and anxieties which the condition can provoke in others.



Feeling safe

Introduction

We know how important personal safety is to older people. Bowers et al (2009) found that feeling safe and secure, alongside feeling connected, was one of the 'keys to a good life' for care home residents. Nolan et al (2006) identify feeling secure as a fundamental building block for older people in care settings in their 'six senses framework'. They also recognise the link between older people's and care workers' feelings of security within the culture of the home.

Older people often choose to move (or are moved by others) into care homes to increase their personal safety: independent living is judged to have become too risky, as a result of memory loss, sensory impairment or mobility problems. Some (OFT 2005 estimated around 6% of all admissions) leave their private homes in direct response to experiences (or fears) of crime, anti-social behaviour or abuse.

Residential or nursing care is likely to be safer in many respects to living alone in the community. Staff are on site at all times so the risks of falling, getting stuck in one position, or wandering off should be significantly reduced. Common personal safety concerns for older people living in the community (Moore 2010, Gordon & Buchanan, 2013) – such as doorstep crime, street robbery or burglary – should be virtually eliminated within the secure, staffed care home environment.

However, care home residents may face other risks to their safety and wellbeing. There have been high profile cases of abuse and neglect by care home workers and other health and social care professionals; family and friends may also continue (or begin) to abuse emotionally, financially or physically. PSSRU (2011) found that 98% of care home residents in their sample said they felt safe in their care home, though the study did not explore in any detail what made people feel safe.

Our findings

As in the PSSRU study, most of those we spoke to were very clear that they felt safe; a small minority said they did not.

'Feeling safe' meant different things to different people, shaped perhaps by their particular fears, vulnerabilities and any recent negative experiences. People talked about physical safety (e.g. in relation to falling or medication), safety from others, and emotional safety – such as having someone to confide in and being able to trust those on whom you are dependent. The influence of media reports and high profile safeguarding cases in older people's homes was evident in many of our conversations – some people, when simply asked if they felt safe, immediately replied "oh yes, nothing like that goes on here!"

Some people confirmed that they felt safer living here than they had in their previous setting. Some had been living in other care homes where they did not feel safe and happy, due to the size or policies of the home; a few people had moved from situations in which they were vulnerable to harassment and anti-social behaviour (one person with a learning disability explained that 'kids were taunting me' in the flat they lived in previously); another had lived next to a river which tended to flood and someone else had been staying with her son, which she liked, but he had been suffering from severe depression. All of these people were clear that they felt much safer now.

- ▶ You are confident you are getting the right medicines (concerns about this put one resident off the idea of going to stay with family over Christmas);
- ▶ The environment is calm: “I should hate to live in a place where they were shouting at each other, you couldn’t relax, could you?”
- ▶ Call systems and buzzers generally made people feel safe, especially where they felt that staff responded quickly to them (though the constant noise from them was a source of stress for some);
- ▶ Feeling that your money and belongings are safe – one woman explained that she felt safe because her daughter was looking after her money and she always kept her handbag next to her;
- ▶ Good accident prevention: one person was reassured that there was a grille on the window to stop you falling out;
- ▶ Some people described the physical security of knowing that access in through the front door was carefully controlled; a few people told us they felt safe when they were in their own room, especially with the door locked;
- ▶ Feeling confident that you could go to the manager if you had any problems in the home; that they would take you seriously and respond effectively;
- ▶ For a couple of people, not seeing the Police was evidence of it being safe;
- ▶ Being able to do things (like going to bed) when you want to;
- ▶ Having a variety of people around you: ‘Different people make me feel safe’
- ▶ Some people were very clear that their main fear was of a (repeat) fall – they felt safe when the staff were supporting them to get about but didn’t want to risk trying to move around on their own;
- ▶ For those who went out of the building on their own, it made them feel safe that staff would know if they didn’t come back – as one person with a learning disability explained, “in case someone gets us”;
- ▶ Having someone to ‘anchor’ you improved the sense of safety, especially for people with dementia: one person explained that it would make her feel safer to have someone to talk to ‘who knows me from old’; a relative we spoke to felt that it made her sister feel safer that she was in a small, homely and familiar place where staff had the time and energy to continually reassure her about where she was, how she got here and who the people around her were – something we observed ourselves;
- ▶ Several made the point that the confidentiality and professionalism of staff made them feel safe: ‘they don’t talk to others about me’

A minority of people did not feel safe.
For them, this meant:

- ▶ Feeling 'trapped', 'caged' or held against your will: 'if I could get out I would' – even some of those who were able to get out and about of the home were clear that being able to get out of your room was as important as being able to prevent others from coming in;
- ▶ Being so dependent on others;
- ▶ Not trusting carers and/or family members (e.g. believing that they were being 'doped');
- ▶ Feeling that being safe is conditional on 'getting on well with them and doing what is expected of you'
- ▶ Feeling unsafe in communal areas – perhaps because of the noise or behavior of other residents, or because you feel that others are talking about you or being unfriendly

Practice example: Keepsafe scheme

In at least one of the homes we visited, we noticed a sticker on the front door advertising that the home is a 'safe place' within the Keepsafe scheme. This scheme is funded by the Police and Crime Commissioner and run through Memory Clubs UK. The care home manager explained that the scheme includes a range of care homes, community facilities and local businesses which are designated as 'safe places'. Each resident carries a card in their wallet explaining the Keepsafe scheme. The idea is that, if they get lost or get into other difficulties, they can go to or be taken to the nearest 'safe place'. The Police told us that over 1000 businesses have received training and the scheme has 6000 users.



Chapter 03

Relationships

Our relationships with other people matter as much to us – or perhaps even more – as we get older. They may provide a link to the past (and, in the case of grandchildren, the future); a chance to relax and ‘be ourselves’; the opportunity to give and receive different kinds of support; fresh perspectives and the chance to redefine ourselves (Blood 2013).

One Norwegian study (Slettebo 2008) described the experience of nursing home residents as “safe but lonely”. Although most felt much safer than they had done living in their previous homes, many told the researchers that they felt isolated, lonely and disconnected from family and friends, from their local communities, and from staff who did not have enough time to connect with them. Previous national consultation with older people with high support needs (including those living in care homes) suggests that, whilst people value feeling safe and secure, the ability to enjoy meaningful relationships, to make a contribution to your communities and to get out and about if possible is at least as important, if not more so (Katz 2011, Bowers 2009).

In this chapter, we begin by presenting our findings about the contact and relationships our sample of residents has with family and friends outside of the home. We then consider friendships and interactions with other residents, before turning to the role of care staff. We discuss the role of managers in more detail in chapter 6 (Choice, voice and control).

The people we spoke to have a huge range of contact and support from family and friends. Some people do not have any close surviving relatives, or any who are willing and able to visit; others seem to have visitors every day. Some family members play an active part in the life of the care home, volunteering and befriending other residents as well as their own loved one. In some homes, members of staff also introduced their own family members to residents, and they played an active part in the life of the home.

Receiving visits was clearly the highlight for many people we spoke to – some felt it was the key thing that made their life in care good:

“As long as I’ve got my family, I’m alright. And my friend who comes once a month. Otherwise I’d be very lost and lonely. I wouldn’t know who to chat to.”

Visits from much younger relatives and grandchildren were particularly valued: a niece with an interesting job or grandchildren to run around the garden brought variety and stimulation. One interviewee explained:

“My grandchildren came to visit and all of us elderly came to life, they were just playing ball and we joined in!”

Family and friends outside of the home

Those who had local and supportive family received various types of support from them. In addition to visits and phone calls, this included: helping them to find and move into the home; sorting out finances and selling property; taking them out for trips – to shops, garden centres, cafes; bringing in things to keep them occupied – from wool to library books. One person explained that:

“My daughter gives me a tremendous amount of support, because she’s my memory”

“I don’t see him often, in fact, I can’t remember the last time I saw him. I do miss him because it’s been a while now.”

Many people lamented the fact that their “friends are getting older”; however some did still have very dedicated and active friends. One person told us that an old friend had driven up from London the previous day; another man told us that his friend who he met in a prisoner of war camp still visited him every day, bringing him beer, sweets and razors.

Some told us how much they missed their deceased partners. A few people were unable to see their spouses because one or both was too unwell to visit the other. One woman explained that her husband was in a home about 10 minutes away; due to dementia he needs a higher level of care:

One couple were living together in the home, but unable to share a bed because there are no joint rooms: “I miss being in bed with her”. Although we did hear some examples of individual staff members going the extra mile to support residents’ marriages, we nevertheless heard examples of practice which suggested that older people are all too often seen as single de-sexualised units, rather than members of couples – whether present or past; heterosexual, lesbian or gay (Blood 2013).

“I haven’t got a husband or a mother.....they’re all gone!”

For some people with dementia, it seemed that the pain and loss of losing their own parents felt recent and subsequently still quite raw, even though they must have died many years ago:

Many of the older residents told us that their own children had serious health issues themselves – one was in a specialist dementia home; one had schizophrenia; a number told us that an adult son or daughter had died.

We met many people whose families were very scattered – children who had moved to Australia decades ago, or who were living in the North of England with busy jobs and young families. Some older people had moved to be closer to family but they recognised the price they had paid for this was that they did not have a local network prior to moving into the home. Others had stayed close to where they lived but did not receive many visits from family who were living at a distance.

“My daughter is coming in today, but that’s in her lunchtime. I don’t expect her to come – she just comes when she can and I accept that.”

Many seemed philosophical and understanding of their children’s and grandchildren’s circumstances and did not want them to feel guilty or give up too much of their time visiting them:

Others clearly felt abandoned by their families and found this very upsetting:

“My family have pretty much given up visiting since I moved into care – it’s almost like they think “that’s him, he’s gone”. I am happy here but you still feel lonely when your own family don’t want to have anything to do with you”

One woman explained that, although her son lives nearby, he only visits a couple of times a year: "he says he doesn't like to see me in the home". There is clearly a role for homes themselves and for the wider community to challenge, support and mediate in cases like this.

We heard a few examples in which family involvement had been less positive: a woman whose family come to the home and shout at her (perhaps because they cannot come to terms with her dementia?), leaving her upset for days afterwards; and a daughter who been misusing her mother's money (though we were reassured that this situation had now been rectified with the support of another daughter). Others felt that, out of good intentions, family members had pressurised them to come into care, when they wished to stay in their previous home.

A few people with dementia expressed anger or deep mistrust of their relatives. It was difficult in these situations to assess how much these feelings were based on reality; however, these emotional responses have resonance in terms of how people are feeling about life or their situation at that moment in time.

Good practice: what are care homes doing to support relationships?

- ▶ Welcoming family members: Staff "know the names of my family and my relatives and they make a fuss of them when they come to visit"
- ▶ Relatives also told us that they value being kept informed – for example, the home telling them that they have just contacted the doctor, or that their loved one has had a fall. They appreciated good systems for booking outings – "if I put in the home's diary that I am going to pick my wife up to take her out; they will have helped her to get ready and she will be waiting when I get there"
- ▶ Supporting residents where family relationships are more challenging – e.g. we heard about staff members providing emotional support after a difficult family visit; helping a woman with a Learning Disability try to trace her mother via the Internet. One manager explained that they will contact social services or try to arrange an advocate if they feel that family are preventing their relative from accessing their own money unreasonably (and this may include paying for a landline or a daily paper), or perhaps even taking money from them.
- ▶ Allowing residents to host private parties in the care home – one person told us that she had recently celebrated her birthday with a small private party in the home's conservatory, which four generations of her family had attended.
- ▶ Taking a positive approach to risk-taking to enable couples and friends to go out of the home together. In one instance, a care home manager had helped a couple to celebrate their wedding anniversary with a meal out. She had driven them to the restaurant then sat on a nearby table with her own family. Another home had responded positively to a wife's suggestion to take her husband out to the tea dances where they had first courted. Now a minibus takes a number of residents out to the fortnightly event.

““ We are happy together ””

We got the impression that, for a number of those we met, it was their friendships with other residents that really made their lives good – or at least bearable. We met a few residents who had known other residents prior to moving in. We met pairs and small groups who had developed deep bonds: like the two residents who sat side by side on a small sofa all day and held hands at times. Elsewhere, one resident explained:

““ When I met x we just clicked. We have the same wicked sense of humour and we come from similar backgrounds – we both had responsible jobs.””

Other residents

We were struck by how much mutual support we observed or heard about between residents, and how many people

- ▶ 'Bringing someone out more' into the communal areas and to group activities within the home: "I suppose it makes a difference if you've got someone to go with";
- ▶ Orientating people who are confused, by reminding them where they are, how they got here, and how to find their way around;
- ▶ Making sure that fellow residents with high support needs get enough to eat, by suggesting other dishes they might prefer, alerting staff that they need help, or that they should be given bigger portions; when one resident dropped her fork at the dining table, the others said, "Tell us love and then we'll speak up for you"
- ▶ Helping people who are struggling to communicate "they [other residents at my table] helped me a lot because I couldn't remember what things were called" [soon after a stroke].

Popping in regularly to see a neighbour who is unable to leave their room without support

- ▶ Knitting bed socks for other residents
- ▶ Supporting each other when upset
- ▶ Saving your place at dinner: "X [another resident who is 'a very good friend'] looks after my serviette – she won't let anyone else touch it! She never forgets, even if I come down late, she won't let anyone sit in my seat and she's got that serviette!"
- ▶ Making drinks for people
- ▶ Picking up bits of shopping for other people when out

Most people described their relationships with others in the home as friendly, though inevitably there were tensions and difficult characters (whose behaviour was sometimes exacerbated by dementia)

“X has got a hell of a temper but x has dementia – the majority of them here have”

“We were a very happy family; there was a crowd of us.... There's just a few of us left here now. But it's not how it used to be..... We were like sisters.”

Some people clearly felt that communal living was a strain – at least at some of the time; the noise can be stressful and the social interactions challenging. Having the option to be private in your own room was valued by everyone, but some were adamant that it provided refuge from the communal areas.

Others missed residents whom they had got close to but who had died or moved on. As groups of friends form then disappear, the whole experience and atmosphere of the home can change dramatically for people.

What can care homes do to support these relationships?

The older people we spoke to told us that the following factors helped to promote the development of relationships and support between residents:

- ▶ Not having rules which get in the way of social interaction: “the first home I was in was a strict one – we couldn’t even go into each other’s rooms”;
- ▶ Considering the location of people’s rooms in the building (especially people who cannot get around the home independently) so that neighbours wave as they pass and are more likely to drop-in (assuming they want this!);
- ▶ Balancing this with making sure that people always have the option to be private and that this is respected, for example checking regularly whether those in their rooms would prefer their door open or shut;
- ▶ Dinner times are a key opportunity for people to make friends - having a system which allows people to sit on different tables at lunch if they want to (perhaps because they have fallen out with the person they have been placed next to, or just because they would like a change and the opportunity to mingle);
- ▶ Finding an appropriate way of introducing new people to the other residents to help them settle in;
- ▶ Finding a way of updating friends on the progress of a fellow resident (e.g. in hospital) without jeopardising confidentiality – this could be discretionary, based on who the known support network of that individual is, or more formal approval could be sought from the resident to pass on news and messages;
- ▶ Giving residents opportunities to make a contribution and provide mutual support, and valuing this when it happens.
- ▶ Making the communal areas welcoming and conducive to social interaction (i.e. not just a ring of chairs around the edge of the room and a television on loud in the middle, unless people are definitely keen to watch it, keeping other noise – e.g. from staff or buzzers – to a minimum so people can hear each other to talk or just sit peacefully together);
- ▶ In larger homes, facilitating some small group activities so people can get to know each other; or introducing people who share interests.

“I’ve never been here before – it’s my first time, I don’t live here. We all get on though, don’t we? We put up with each other [laughs]!”

When asked what makes a good care home, many people replied, without hesitation, that it is the staff that make all the difference:

“The staff – it’s definitely the staff – just staff that are good to you, basically.”

In the majority of the homes we visited, people praised the care staff very highly; however we did hear some less positive feedback. Poorer practice seemed to be linked to organisational issues, such as lower staffing levels and culture of ‘them and us’. The staffing level seemed to vary quite a bit from home to home and subsequently there was considerable variation over how much time staff have to interact with residents.

Residents and relatives place huge value on the continuity of staff – where turnover was high (or agency staff were used regularly), this impacts adversely on residents’ ability to form relationships with staff, to have a say, and to feel safe and orientated.

“The girls they come and go, they don’t seem to stay long.”

Some of the larger homes we visited had created a home within the home for people with more advanced dementia: sometimes this was called the ‘dementia wing’, sometimes the ‘extra care unit’. There can be challenges in managing the relationship between these smaller units and the rest of the home: as one resident pointed out, there is a risk of this arrangement creating a sense of ‘them and us’ amongst residents. However, many of our conversations confirmed the existing evidence (e.g. Verbeek et al 2014) that smaller, ‘household’ style arrangements can benefit those with those more advanced dementia by helping them to build relationships and familiarity with their surroundings in a calmer environment. As one member of staff working in such a unit explained to us:

“The staffing is so high here – so you can get to know them better – it’s much more relaxed than the rest of the house. We’re like a family down here now”.

What makes staff ‘good’ from residents’ perspectives?

- ▶ Taking time to talk and get to know them – “they come in and have a chin-wag, especially in the evening – and that takes up a lot of time”
- ▶ Respecting residents’ choices and fitting around these flexibly: “they never moan; it’s just what you want to do. I didn’t have a very good night so I’ve stayed in bed all day!”
- ▶ ‘Kind’, ‘helpful’, ‘pleasant’
- ▶ Skilled and well-organised: ‘they know what they’re doing’
- ▶ Professional: respecting resident confidentiality, not complaining to residents or arguing with each other openly
- ▶ Little treats and gestures of personal care – like buying in baguette for one resident who had lived in France
- ▶ Having a good sense of humour and having a laugh with residents
- ▶ Being prepared to go beyond the call of duty occasionally, e.g. taking someone to see their seriously ill friend in London on a day off
- ▶ Being prepared to share some of their own lives so the relationship is not just one-sided. We heard about staff bringing in their pets and babies to show residents and even inviting some residents to their wedding. One manager said, “We know residents’ families, why shouldn’t they know ours?”
- ▶ Responding as quickly as they can when you press the buzzer
- ▶ Providing a good service: laundry, food, cleaning, personal care, etc

A few residents and relatives expressed concerns about care staff pay and conditions. One resident told us:

“[The care workers] really care – they are more like friends really..... one night, I was in a terrible state..... I just had a horrendous night and they didn’t leave my side for the whole night – they were there at my bed, they lay down next to me, they held my hand.... You can’t put a price on that and they should be valued, they should be earning more”

Examples of less positive interactions with carers included:

“They’re all good but they always seem to say, “I’ve got to go, I’m in a hurry””

- ▶ Carers being too busy: they are ‘just rushing around’; “we wouldn’t bother them”;
- ▶ Mildly patronising greetings and comments, such as “You’re doing very well, love”
- ▶ Comments which suggest that staff are very much viewed as being in authority – “if they let us”
- ▶ Not knowing carers’ names
- ▶ Carers rushing in and doing things, like plumping a pillow behind someone without warning, which makes them wince with shock/ pain
- ▶ One of the carers saying “they’d chuck us out”, if we ran out of money and couldn’t afford to pay – even if said in jest, this was insensitive, given that many residents feel anxious about affordability
- ▶ Having loud conversations with each other in residents’ areas: “All they want to do is come here and talk about last night’s episode on television”
- ▶ Responding to reports of a resident nearly falling and being caught by someone with laughter
- ▶ Passing by residents who appear to be uncomfortable or in pain, rather than stopping to see if they need to adjust their position.

One resident’s comments reflected the messages of a number of recent inquiries and studies on the care home sector (Warmington et al (2014), Kennedy (2014), Owen & Meyer (2012):

“The staff are very nice, very caring, but they’ve got so much red tape..... I would like to see less red tape, they are too busy.”

Going out
and links with the
local community

There was huge variation in the extent to which individual residents went out of the home. Some people went out most days – with family, on their own for a walk, on organised trips from the home, or with a carer to the shops. Some went out regularly – perhaps a weekly trip to the pub, the shops, for a drive or a dog walk with a relative; others went out very occasionally – on the odd organised trip, or to family for Christmas. Some people had not been outside the home for as long as they could remember.

Those who hardly ever went out had mixed feelings about this:

“My children would take me out if I wanted to, but I’m not that bothered”

“I tried to get away once. I’ve been caged ever since. Surely I have a choice as to whether I live here or not? I haven’t been out at all – that’s why I tried to make an escape.”

There was massive variation in the amount of trips out organised by the homes we visited. Some of the larger homes had their own minibus and activity coordinator. Interviewees told us about organised trips which included:

- ▶ Going to the local school to see the nativity; or to another care home to watch a pantomime;
- ▶ Regular trips to a tea dance;
- ▶ Trips to the countryside, the docks, for a picnic or an ice cream in summer;
- ▶ Going to a church service
- ▶ Garden centres
- ▶ Pub lunches
- ▶ Day centres and lunch clubs
- ▶ Longer trips – to the beach in summer; at the Learning Disability care home, they had been to Butlins and even Paris!

“It’s not an exaggeration – sometimes we go nearly every day [on a bus trip out, organised by home]. They really put themselves out to take you out of the building and into the countryside as much as they can – of course, some people never want to go but I always like to go and see everything. I don’t want to miss anything!”

Many residents also clearly valued smaller impromptu trips out – either on a one-to-one with a carer or in a small group. Examples included:

- ▶ Going out to the local shops to get a few bits and pieces – or further afield, e.g. to buy new slippers
- ▶ Going to the local hairdressers
- ▶ A woman with dementia who was taken to see her grandfather clock which is in a local museum by a carer, who took a photo of her standing next to it.
- ▶ Going out for a little walk from the home.
- ▶ Being supported to do things like go to the local GP or the polling station.

- ▶ “Exercise and fresh air – really important”
- ▶ “It’s nice to get up on the Cotswolds when the weather’s reasonable and have a good long view”
- ▶ “I don’t come from round here so it’s new to me”
- ▶ “It’s a lovely town and a nice area”
- ▶ “I like going to town – just looking around”
- ▶ “I’d like to go to that place where you can see all of the trees going orange and brown..... I like beautiful things”
- ▶ Good to be able to get a few bits of your own shopping in
- ▶ “I like sitting in the front seat if we go out. Then I can tell them the way and point out where everyone lives”.

What did people value (or miss) about being able to get out and about?

Residents told us about some of the **barriers** to being able to get out and about. These included:

- ▶ Mobility and general health: some people told us they were recovering from a recent heart attack or fall; others explained that their mobility had simply deteriorated over time;
- ▶ Transport: having people who could give you a lift (especially where most of your peers no longer drive); being able to get in and out of cars or taxis; whether or not the home had a minibus (and this was more difficult for the smaller homes) – though even where it did, one resident pointed out: “it’s not to run you here, there and everywhere”;
- ▶ Weather – many people said that they do not go out in the middle of winter; some told us about other problems – like hay fever or swollen eyes – during the summer months;
- ▶ Accessibility of relatives’ homes or public places;
- ▶ Confidence: “I’m too scared of going out and falling again. I’d rather stay in and be safe”;
- ▶ Care home policy – not being allowed out (see discussion and examples in the section below);
- ▶ Not enough staff/ no available relatives to take you;
- ▶ No or very few organised trips out from the home;
- ▶ Continence: “There are trips all the time – I don’t go on those because of my bladder problem – they’re all women and I can’t suddenly say “Stop! I want to have a pee”. So I don’t go on those”

“I’m just shut in here – day after day”

“Unfortunately I can’t get out for walks anymore – I can just about manage to walk around here on my frame but no..... I can’t get out of here. I’m here until I die”

01 Using local amenities

Organised trips out were clearly valued by some; however, others stressed the importance of being supported to access 'normal' day-to-day activities in the local area. The manager of one home explained that residents are encouraged to go out of the home if they can - to the local shops, the bank, the hairdresser, the GP, etc:

"We go out with people to the polling booth to vote, we go for walks. If a resident pops in here to say they fancy going to the shops, I'll say give me 10 minutes and I'll come with you. It can be hard for care assistants to drop what they are doing, they have such a lot of jobs to get done, but I can, and I always will if I can".

Another home has close links with the church opposite. The vicar does a monthly communion service, a carol service and an Easter concert at the home.

Being able to do this depends on what there is locally: some homes did not have these kinds of amenities on the door step. In some areas, there may be opportunities for homes to link up with (or initiate) local 'dementia-friendly communities' or local community-led networks under the Barnwood Trust's You're Welcome initiative. For more information, www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1843 and www.yourewelcome.to/

02 Inviting volunteers and local people in

One home we visited is part of a scheme called 'Young Neighbours', run by Cirencester College – this matches up security checked young people with care homes and individual residents. Young people chat to older residents or play Scrabble; one even wrote up part of a resident's life story for her. One volunteer we met during our visit explained that she had always wanted to do something like this and that she really enjoyed her visits to the home. Many volunteers are considering careers in health or social care and one group of residents told us they had written an impromptu reference letter for one of them, to strengthen their university application. Another resident who receives a regular one-to-one befriending visit from two different young people explained:

"I enjoy these visits immensely – they like to know my background and I ask them about their backgrounds and it's great, because they are young, because they are nice people, because it's good to spend some time chatting 1-1 with someone like that".

This home also provided a venue for the local 'Knit and Natter' group in its dining room. A number of local people came in to attend the monthly group and were usually joined by a handful of residents. This helps to break down barriers between residents and local people and encourages local people to come into the home. One member of the group has since decided to move into the home.

“I think what I need now is an outside visitor – maybe someone from Age UK Gloucestershire.”

Other homes told us of local children coming in and talking to residents as part of their history projects and one manager was considering a garden party in summer to invite in the neighbours. However, whilst there are clearly a number of benefits from developing the role of care homes as 'hubs' for their local communities, this manager was also aware that:

“it's a difficult balancing act – it mustn't feel too public because it is their home”.

Other home managers we spoke to said they would like to encourage more volunteers to come and offer befriending and activities to residents. We were struck by one interviewee telling us how good it was to meet someone new to tell their very interesting (but quite long) life story to. One resident suggested:

There could well be a role here for Age UK Gloucestershire in promoting its befriending scheme and extending it into care homes. We understand that GCPA is doing some work with its member homes, looking at how to make their homes more welcoming to the wider community – in some cases, this may involve simple practical steps such as improving the external signage or front garden.

03 Policy and practice in letting residents go out

We heard of very different policies in relation to letting residents or couples go out alone. Homes clearly have a duty of care to stop those with substantial memory loss from wandering out without staff knowing and getting lost or having an accident. However, some were adopting a 'positive risk taking' approach to letting residents with and (in certain circumstances) without capacity off the premises. Others had a much more cautious approach.

We met a couple in which the husband has quite advanced dementia and lives in the home and the wife has early-stage dementia and can get disorientated too. They told us about the nursing home he had been in previously and how the wife had complained because the home would not let him out. When they moved to the residential home he is at now, the manager and wife worked out where it would be safe for her to take him. They now go out independently to the local park, café and pub, within clear boundaries, so that they are within reach of the home staff if needed. The manager reflected on balancing the risks in such situations; she said it helps that there is strong family backing in this case, but that it took an assessment by an Occupational Therapist to convince relatives it was a good idea.

In another home, there is a secured 'extra care unit' within the home. Most of those living in this part of the home would need significant assistance to go out. But residents who live in the rest of the home and have mental capacity can mark themselves in and out on the Board in the entrance lobby. One resident described enjoying little walks around the grounds and nearby park, wearing an emergency pendant to call carers if there is a problem. The manager explained:

“If we say ‘no’ to those that want to go out, we are effectively holding them prisoner. If they were living in their own homes, they would still be able to go out if they could and when they wanted to.”

“ [Sadly, near end of interview, looking round small room with no outlook] “This is all there is for me”

When we asked residents about any contact they had had with the police since living in the care home, some told us about their personal connections to the force – a late husband or father who had been in the force. The majority of people could not recall ever having seen the police at the home; one or two gave us examples, such as the police attending some time ago in response to money having gone missing from the office, or whilst searching the local area in response to a serious incident that had occurred outside of the home. Many of the people we spoke to could not remember whether they had seen the police or not: [in response to the pictures of police officers and being asked if they ever see them] “Police? I don’t think we do”

Interestingly some residents interpreted the fact that they do not see the police as evidence of the home being safe and secure; others found it hard to grasp what role the police might play in promoting the wellbeing of older people living in care homes.

““Yes, I feel safe and secure. Don’t see the police.””

““I don’t really see that the Police could do more on this – I mean we don’t ever see the Police in here.””

A couple of the homes we visited did seem to have more of a relationship with the police. One manager explained that:

“We have had the community police around here. They come quite often and bring round leaflets (e.g. about safety). They are very good locally.”

In another home, we heard that one of the staff members had a personal connection to the force and that, as a result of this, some of the local police choir come in and sing at the home from time to time.

““[In response to photo of police officers] “Police - no, they don’t come in. They look nice, I wouldn’t mind them (laughs).””

Activities and media

Activities and interests

There was a huge range in the amount of organised activity going on in the sample of homes we visited – some had activity coordinators and an extensive programme, ranging from Chinese keep fit to Body Shop parties, with visits from singers, dogs and local schools; in some of the homes we visited, residents told us that very little happened – some seemed quite happy with (or at least accepting of) this, others presented as bored and distressed.

“ I have to amuse myself, there’s nothing really that goes on here. ”

There was also diversity in the extent to which different individuals wanted to get involved in group activities within the home. To some extent, this was shaped by health, cognition, mobility and the mix of other residents. Personality and gender also played a key role – men seemed less likely than women to want to participate in organised activities, though this was not true of everyone.

“ I spend most of my time in my room. I’m not particularly sociable, never was ”

Others went on every trip, had made strong friendships and were the core residents participating in most activities. People who were not sociable appreciated the respect shown for their privacy and choice of solitude. However, there is a balancing act here if the ‘inverse care law’ (in which those who are the most able, independent and well-networked receive the most attention from staff) is to be tackled.

Television provides company and a means of keeping in touch with the outside world (see section below) for many. Men particularly valued being able to watch sports. However, whilst almost everyone seemed to have a television in their private rooms (where they could exercise choice over what, when and how loud they watched), there were mixed feelings about the television being on in communal lounges.

“ We’re persecuted with the TV on. We’re not allowed to speak here! ”

We witnessed televisions just being on in communal lounges, creating noise without anyone really seeming to be watching them properly. We spoke to some residents who preferred the ‘quiet rooms’ which some homes offered – it was nice to be able to sit quietly and maybe chat to others without the television on but without having to retreat to your own room. Some respondents regretted that group activities were poorly attended because everyone goes back up to their own rooms to watch TV after lunch.

“ There’s too much going on to watch television in here! ”

Chapter 05

Activities and media

“I miss my garden – I like cutting grass and just pottering about, pruning and stuff. I want to get back in my garden and my shed! That shed was a mess but I loved pottering about in there.”

Quieter and one-to-one activities

Some of those we spoke to had ideas for quieter, perhaps even solitary activities they would like to have the support and/or resources to do – such as large print puzzles, or crafts like rug-making. Another respondent explained that, although there was a full activity programme at her home, “on the whole, I like quiet and we’re supplied with noise!”

Some homes seemed to be good at bringing activities up to people who cannot or do not want to leave their rooms. Some people told us that staff had been up to their room to do quizzes with them on a one-to-one basis. Visiting therapists, such as beauticians and therapy dogs had been around individuals’ rooms in one home.

Gardens and outdoor spaces

Many people told us that they were (or had been) keen gardeners. Nowadays, some just enjoy sitting out in the garden when the weather is fine, or looking out at it from indoors. Birds and squirrels brought added interest. However some – like the man quoted above – longed to get more involved in the home’s garden. In one home, we noticed that there were bulbs and bowls and bulb fibre waiting to be planted up on prominent display with an invitation to plant a few bulbs if you feel like doing so.

A ‘whole home’ approach to activities

We heard how one activity coordinator is developing a “whole home” approach to involve ALL staff in small ‘informal’ interactions, not just group “activities”. Some staff felt they did not have time to do this, but the coordinator has produced lists of ideas for simple activities which care workers can use with residents on a one-to-one basis if they have either 5 or 10 minutes.

One of the homes we visited is working with Orchard Trust Training, who are based in the Forest of Dean and run courses and meetings for activity coordinators and champions across the county. They will also be launching an e-learning course from May/ June 2015 www.orchardtrusttraining.co.uk

Communication and media

Keeping connected to the outside world was crucial to the quality of life of many people we spoke to. Some people used the phone or even the Internet to do this; others watched television, read the newspaper or listened to the radio.

Phones

We included questions about access to phones where possible in our conversations, since we felt that being able to make a private call might be one route by which residents could contact a social worker, advocate, helpline or even the police if they needed to.

- ▶ Quite a few of the residents we spoke to – particularly those who either did not have any relatives at all, those with significant communication issues, or those whose relatives lived locally and visited regularly – did not feel they had much need of the phone.
- ▶ The majority of the homes we visited allow residents to have a landline installed in their own rooms provided they pay for this. Mobile reception was not always good in some locations; the other alternative for people who did not have a private phone was to call from the office (mostly just to make arrangements or in an emergency); in smaller homes, it was generally easier than in larger establishments to allow residents to make or receive private social calls (on a handset in their own rooms).
- ▶ Residents' individual access to and use of the phone varied enormously both between and within care homes. For example, we met someone who had a specially adapted phone in her room, with boosted volume and direct dial to all her family, so she could speak regularly to relatives; another was in the process of getting the phone number from their former home transferred to their private landline in the care home. We met a woman who was still very active as a lay reader and organist in local churches and receives lots of calls on her private landline making arrangements for this (including who will give her a lift).
- ▶ Family members generally seemed to play a key role in access to phones, for example, supplying, replacing, setting up, or – in some cases, not allowing people to have - mobile phones.
- ▶ At the other end of the spectrum, we met people who were not able to use the phone for a range of reasons: one explained, "I've forgotten how to use the phone now"; others could not see the keys or move their fingers in order to dial. Many of those with learning disabilities explained that they would not be able to use the phone without support, though one man clearly remembered all the numbers!
- ▶ Some people who did not have a phone wished they did – not being able to call up relatives seemed to reinforce the sense of passivity:

“A telephone would be nice..... I could phone my daughter if I needed anything – I just have to wait for her to come.”

- ▶ Affordability was clearly an issue for a number of people:

“You can have a mobile but they're too expensive – my daughter says, “we can't do any more”..... if we didn't have to pay so much”

“ I use my TV a lot for the news – I like to know what’s going on in the world, it doesn’t cost (like a newspaper). It keeps you involved in the world ”

TV/ newspapers/ radio

A significant minority of those we spoke to told us that they receive a daily paper; others get the paper passed on by another resident or by visiting friends and family. In some homes, there was a copy of a tabloid and/or a local paper and perhaps a few magazines lying around in the communal lounge. Some people told us that they particularly valued the local paper since it helped keep them connected to news in the communities from which they come, particularly the obituaries.

One participant pointed out that they did not pay any extra for their daily paper; but for others, cost was clearly a consideration. Television and the radio provided alternative means of keeping in touch with the outside world, which was free and accessible for those unable to read the papers:

Internet

In around half of the homes we visited, residents told us that there was internet: usually this involved a computer with an internet connection in one of the communal lounges, but some homes also appeared to have Wi-Fi broadband too.

We met two individuals (in two different homes) who had tablet computers in their own rooms, through which they accessed the internet. One person told us:

“ I use it but only for certain things – I can send people letters..... I watch programmes that I miss on the television on the iPad. I don’t read on it. ”

“ I wouldn’t say I’m a techie, but I’ve always tried to keep up with the youngsters and it just comes to me. I thought, if I couldn’t do this, what would I do? How would I keep in touch? ”

The other woman described how she uses Skype and Facebook on her personal tablet to keep in touch with her internationally scattered family. She explained:

A handful of other interviewees told us that they either used to use a computer (but had not since moving into the home), that they occasionally used the care home’s computer, or that they would like to learn to use a computer. Although many of the remainder said they were not interested, there was a striking number who expressed interest in their potential:

“ I would like to use computers – I guess I kind of missed that one. My family all use them – they’d know exactly what to do with one. ”

In two of the homes we visited (one of which was the Learning Disability home), the manager told us about some of the ways in which they promoted use of the communal computer by residents. One manager told us that, since they had been able to recruit an activity coordinator, she had been able to provide dedicated support to individuals and small groups of residents to use the computer. Some of the things residents enjoyed doing on the computer in these homes included:

- ▶ Internet shopping;
- ▶ Listening to music, e.g. going to the Classic FM web site, or having a 'jukebox' session, searching for old songs;
- ▶ Sending e-mails: a couple of people told us that they could not type independently but that a member of staff had set them up with an e-mail account and would type emails for them if they dictated;
- ▶ Using Google Earth to find places they had a connection with – in one case, we heard that an activity coordinator had done a 360 degree tour of someone's old school with them;
- ▶ Watching videos, e.g. on You Tube

We felt that some of the passions which other residents told us they missed so much – holidays, golf, playing the piano, theatre, etc, could (to some extent!) be relived through computer, touch screen and Wii technology. There are a range of practical resources available suggesting apps, web sites and approaches to use in supporting people with dementia to use IT (see Resources section at the end of this report).

Choice, voice and control

Moving into the care home

“ In the end I stopped fighting because then you get a lot more help, but I think now I’d be all right in my own place.”

The Health and Social Care Information Centre (2013) has identified a relationship between how safe service users feel and how much they consider themselves to have control over their daily lives. Previous studies have also highlighted the loss of control and autonomy which some people experience when they move into a care home (e.g. Bowers et al, 2009); especially when they feel as though the decision to move has not been their own (Tak 2011). This, combined with the upheaval and disorientation of a move at this stage of life (especially where someone has a cognitive and/or sensory impairment), can have a profound impact on a person’s sense of security and personal identity.

We were struck by just how difficult it is for people with dementia to move and truly settle into new surroundings. We met people who had, according to staff and other residents, been wandering around the home, trying to find their way and make sense of where they are for years. The design of some buildings – with long corridors – does not help here, though some of the newer, purpose built homes we visited had incorporated simple dementia-friendly design principles, with different wall and door colours and individual ‘memory boxes’ to aid orientation.

Making sure that people feel as in control of their move as possible was felt by those interviewed to set the tone for the whole stay in care. As one person said when we asked about life in the home:

“ It’s very pleasant. I choose to come here.”

In some cases, people described how they had felt pressured by family, hospital and social workers to come into care when they had wanted to return home (which, in one case, had been an extra care housing scheme) and believed they could have coped there. Some had come in for respite and agreed they needed this but felt they could have returned home after this short stay. We heard from staff that family members and social workers sometimes lie to older people about where they are coming and how long they will be living here, expecting care home staff to either collude or explain on their behalf, which is hugely unsettling for the older person and puts staff in a difficult position. The media reports about care homes (which tend to increase families’ feelings of guilt and fear), combined with pressure to discharge people from hospital do not help.

Many of those who knew the local area before moving into the care home had succeeded in maintaining at least some of those links. It was very hard for those who had moved into the area to build these from scratch from within the home and this group were much more dependent on staff, other residents and nearby family (if they had them) for their social interaction.

When we visited the Learning Disability home, we were struck by the contrast in the experiences of those getting older in care, with pre-existing disabilities, compared to those in older people’s homes who had got older, developed health problems and then moved into care. Many of those in the Learning Disability home had been living together for the past decade or so. There were still tensions and frustrations between residents at times, but this was a very settled group, compared to the constantly changing communities in older people’s homes.

“ It does take a while to learn to live here.”

Chapter 06 Choice, voice and control

Having a say

“ If I tell them there is something I don't like, they usually take care of it.”

The majority of people we spoke to said they did not have any complaints and that, if they did, they would speak to a member of staff, usually the manager. Most people had a clear sense of who was in charge and many used their first name, though some spoke of 'the management'. Some people offered examples of feedback they had given or suggestions they had made – some of these had been acted on; some had not. Some residents explained how a compromise had been achieved, given the constraints within which the home operated. One person explained that 'you have to be assessed for doing things safely' – in their case, the assessment had 'been the barrier'.

Most people felt confident that they could make complaints about the food if they needed to (or just choose something different), however feeding back a problem with a member of staff would clearly be more sensitive. Some people were confident that, if you took a genuine complaint to the management, you would be taken seriously, even to the point where the staff member might be sacked. However, others were less confident – one was emphatic that they would not say anything. Some of our interviewees felt that some of their peers were too timid, or just moaned to each other, without saying anything to staff or management.

A significant minority of those we interviewed used imagery about power and rules and prisons when describing their life in the care home. For some people, feelings of being trapped against their will seemed to relate to whether or not they felt they exercised choice and control over the decision to move to the home in the first place. Some used the word "them" to describe staff, suggesting much more of a 'them and us' culture; and many talked about whether or not they were 'allowed' to do things.

We saw and heard how different managers (and, in the smaller private homes, different owners) have different styles and systems. Some are very 'hands-on' and proactive and go around the home, catching up with residents regularly; in the bigger homes, there may be another layer in the organisational structure. Some managers have an 'open door' policy, however, we saw considerable variation around how this worked in practice, influenced by the location of the office and access to it and the size and culture of the establishment. We noticed that the manager's approach tends to be mirrored by the staff team: if the manager has an open door approach, it feels safe for staff to adopt the same sorts of relationships with residents.

Many of the homes we visited have formal structures for communicating with residents and gathering their feedback. Some hold resident involvement meetings (though there was sometimes a discrepancy between residents' and manager's perceptions of their frequency); some have suggestions boxes (though we did not get the impression these were very well used); in another, we noticed a complaints and feedback procedure (in rather small, dense print) displayed in the kitchen.

“ You could make suggestions and every so often there's a residents' meeting there used to be a file where you could make suggestions too. They're not against ideas.”

Whilst these mechanisms for resident feedback are important, we got the impression that it is the general ethos which most supports (or challenges) the sense of resident choice and control. Are you listened to? Are the things you say acted on (or is discussion and compromise at least attempted?). How much choice do you have in relation to your daily routine?

Having sufficient staffing and good leadership were essential to establishing and maintaining a culture where residents feel they have choice and control. There was an acknowledgement in some homes that the 'jobs' and 'tasks' still need doing but it is all the stuff that happens around this which is really important. There is a risk that system cultures can over-ride care workers' natural approaches and empathy with a job that has to be done.

“ All the staff, the domestics, the kitchen, they're all so helpful, they'll do everything for you – it comes from the top, doesn't it – xxxx [the manager], she's really special.”

What makes people feel they cannot have a say?

The lack of confidence to have a say often seems to be related to ageism and the widely experienced sense that older people's views are of less value than younger people's. Some people expressed low expectations about whether their views would be heard, given their age. One person said:

“I'm too old to have a say – they probably wouldn't listen anyway.”

However, we should not assume that all care home residents feel this way; for example, this woman described feeling more empowered to have a say since moving in:

“I was a mouse before I came in here. I spent my life looking after other people and doing the right thing and when I came in here I just thought – I can live my own life and say what I want to say. But I hate it when other people won't do this – they just bottle it up and moan.”

Several people talked about not wanting to 'rock the boat' or be 'labelled a troublemaker'. Some felt they did not want to grumble about some aspects when they felt very grateful for the good service they received in others; others seemed more concerned about the consequences of speaking up, for example a fear of jeopardising their relationships with staff and the service they receive:

“I was told I could stay as long as I like; some people get sent to hospital and you don't see them again.”

“I keep quiet. They might chuck me out on a cold night!”

Even if this is not a realistic fear, it reminds us of how some care home residents feel the imbalance of power between themselves and the staff very acutely. One person explained that “they over-rule you”; others spoke of feeling indebted or being 'completely dependent on them'. One person explained:

“It's nice to be a placid patient.”

We heard that some residents support each other to speak out. One small group of women we spoke to explained: “We've helped each other, encouraged those who are a bit timid”.

The size of the home and the number and turnover of staff may affect some people's confidence to feed back their wishes, ideas and complaints. When asked whether they felt they have a say in the how the home is run, one resident replied:

“What do you expect now at this stage in your life? There are so many helpers about you don't know one from the other.”

Another explained:
“I notice they're busy. If you can speak up for yourself, you're alright.”

By contrast, in the smallest home we visited, residents felt that staff hardly need to formally consult them because they knew them so well and had such a lot of contact with them. Some people told us they were not convinced it would make any difference if they did complain:

“I couldn't tell someone if I was upset, not even about the food, it just wouldn't have any effect.”

Good
practice ideas

01 Choice over personal routines and food

We were struck how, in the Learning Disability home, people sat down at slightly different times and in different places to have lunch. A member of staff explained that, at residents' meetings, residents get to pick and vote for their menu choices – these are then drawn up into a 10-week menu planner, though there is always an alternative choice on the day for those who do not like or cannot eat the main dish.

This seemed different to most of the older people's homes we visited where, certainly in the larger establishments, procedures and routines tended to be stricter. However, we observed simple acts of good practice where, for example, a member of staff showed someone who was struggling to communicate the different alternatives for pudding, plated up, so they could point at the one they wanted.

02 Opportunities to contribute

At the Learning Disability home, residents were actively encouraged to contribute to the running of the home and be as independent as possible – for example, coming into the kitchen to make themselves a snack or a drink. Whilst this might not be physically possible for those who are less physically able, we

did speak to older residents who might be interested in helping out with cooking, laying the tables or doing a bit of gardening but who made comments like:

“I don't even know what the kitchens look like here. You don't interfere with them”

We found that some individual residents in older people's homes had been given roles, permissions, active jobs, but this seemed to be more ad hoc and based on the fact that they had lower levels of needs rather than being a philosophical approach about encouraging people to contribute.

One manager told us that:

“When we are appointing a new care worker, we ask the residents what they think. We'll leave them in the lounge for a bit, and then ask the residents for their views”.

There is some good practice here from St Monica's Trust in Bristol: they held workshops with the older residents of their extra care schemes to identify what the core components of a care worker's person specification are from their perspective. See Blood, Pannell & Copeman (2012, p.21) for more information:
www.jrf.org.uk/sites/files/jrf/housing-care-practice-full.pdf

03 Recruitment and selection

Equality and diversity

We have described in the previous section how ageism and negative perceptions of age can affect the way residents feel about themselves and their rights.

We also heard from staff at the learning disability care home how people with a learning disability can face a 'double whammy' of discrimination as they get older. Staff here felt that the best ways to tackle this were to support residents to connect with the wider (mainstream – i.e. not just specialist services) community, such as colleges, shops and cafes. They also felt that agencies like Adult Social Care and Age UK need to challenge themselves about how accessible they are to people with a learning disability and whether they might be 'hard to reach' services.

Living in an institutional setting can be a particularly stressful and intimidating experience for minority older people. Previous studies and reports (e.g. Bowes et al 2011, Blood & Bamford 2011, Carr 2013, Age Concern 2006, CSCI 2008, 2008b, Manthorpe et al 2010) have highlighted the experiences or fear of harassment which older lesbians and gay men or older people from religious or ethnic minorities may face within care homes.

Within the Care Home Whispers project, we did not engage with anyone who told us they were (or appeared to be) from one of these minority groups. However, we did have some conversations about equality and diversity issues in care homes with residents, staff and relatives. Issues raised included:

- ▶ Care staff coming from BME backgrounds and/or not speaking English as a first language – relatives told us that this sometimes got in the way of communication and relationship building. However, the culture, management and overall experience of the home can make a huge difference here. For example, one relative told us:

“Mum was being quite racist in the home she was in before [where she was not nearly so well cared for and happy] but in the new home – where there are black workers and workers from other countries, there is no sign of this – just because there is a different atmosphere and she has built up a relationship with them all – she tells me they ‘have a laugh’”.

- ▶ Responses to male care workers: “We still get people saying ‘that’s a woman’s job’. Some staff reported that there are quite different attitudes and values amongst some of the older generation. However, many of the residents we spoke to said that they really valued the input of the men working in their homes (though some admitted it had taken a while to adjust)
- ▶ Gender issues for residents – in most homes, male residents were significantly outnumbered by female residents; some (though not all) of the male residents choose not to participate in group activities; a male care worker felt that the men of this generation (in particular) had been brought up not to express or discuss their feelings
- ▶ Class issues were keenly felt by some residents: a small group of residents in one home told us that they felt the sense of community and friendship between residents was strengthened by the fact that most of them ‘came from similar backgrounds’, i.e. mostly retired professionals. Another person explained

“Just between you and me, why I like it here is it’s not posh – do you understand that? So we can be much more open with the staff and we have laughs and jokes with the staff – it’s just not posh, it’s more relaxed. I did look at another place but when I look back on it now, that would have been too posh. I mean here we use quite a lot of army language which some people wouldn’t understand ...”

Relatives' perspectives



In this section, we collate the key themes that emerged from our conversations with relatives about what mattered most to *them*.

Some relatives told us they had had very different experiences of different homes, perhaps because their relative had been in more than one home or they were supporting different relatives living in different homes. People felt there were a number of factors at work here – staff skills, numbers and attitudes (and sometimes how fluent in English staff were), the culture and management of the home and the personality of the resident.

Staffing levels and skills

Staffing levels were felt to have a huge impact on residents' quality of life:

“I sometimes wonder whether, if they are short-staffed, they put him to bed.”

Another person felt that her mother is sometimes put to bed 'because it's safer'.

In some homes, people reported that 'they are desperately short of staff – a lot leave because they're on the minimum wage - they can't afford to pay for housing and there are few opportunities for progression.

Many felt that staff do an excellent job but some were concerned that people do not need any formal qualifications to work in this sector (in contrast to the requirement for qualifications in virtually every other setting these days).

“The carers are kind and caring but I think they would benefit from more training and a qualification that recognises their skills.”

Another relative witnessed younger carers learning from more experienced carers and felt this was how many of them learn. This makes it all the more important to retain good and experienced staff and ensure that the modelling comes from the top.

Several partners said that having to deal with their loved one's incontinence had been the key trigger for moving to a care home:

“ It makes a huge difference to me that I can go and visit every day but I don't have to get involved in the personal care anymore – I don't know how the staff do it really, but then I guess they are not as emotionally involved as I am. ”

Where their loved ones have advanced dementia, physical appearances – looking well-fed and groomed – are often really important.

“ I go to visit and she's sitting there clean and they've done her hair nicely – maybe she's even had her nails done or she's wearing a bit of jewellery and it's the little things like that..... I guess they do it as much for our benefit as anything else, because she looks more like Mum. ”

Others expressed concerns about variable approaches to the prevention and treatment of pressure sores across different homes. Some people are able to access special mattresses, chairs and other equipment; others do not.

Offering activities, but also taking time to connect and build relationships were valued:

“ The activities are brilliant – there's always lots going on – little trips out in the minibus – Mum used to love all that. She can't do much of it now but the staff love her to bits and it shows. ”

Communication with and involvement of relatives

Relatives told us how important it is for staff to really get to know the resident – to follow relatives' advice and to offer as much choice and control as possible:

“ [My husband] will eat if he can choose – it's like he will get the food if you leave it for him. ”

We heard some negative experiences of staff seeming not to follow the care plan, then experiencing 'challenging behavior' as a result. In one instance, this had led to the home saying it could not accommodate the resident, triggering a period of stress, hospitalisation and uncertainty.

Relatives valued being able to take their loved one out for little trips: one explained how they really appreciated being about to get out and walk and go for tea and cakes in the town. This was partly about the location but it was also about how much staff supported them in this. One partner explained that, if they put in the diary that they would be taking their partner out one day, when they arrived at the home, they would be dressed and ready to go.

Quality of care

Relatives told us how stressful and upsetting it can be to see the language and behaviour of other residents:

“ Sometimes I’m sitting in the home thinking – it’s dreadful seeing all these people in this state.”

They gave the following examples of how homes sought to involve them and how this helped their general feelings about the home and their empathy and relationships with staff and other residents:

- ▶ Relatives being invited to join the Christmas party – getting to know staff, other residents and their relatives means that it feels more like a community
- ▶ Agreeing under what circumstances to contact you – e.g. if your loved one has had a fall or a health incident (and sticking to it)
- ▶ Making time to stop and have a chat
- ▶ Treating you and your relative with respect – but being able to have a laugh too
- ▶ Encouraging you to bring in your dog, your wedding album, etc and then spending time with your loved one reminiscing
- ▶ Not speaking on/ playing around with their mobile phones when they are with residents (and/or you)
- ▶ Having a clear mechanism for gathering relatives’ feedback (e.g. a questionnaire) – then responding to the feedback you provide

Some relatives reported how difficult it can be to find the right (or indeed any) placement for people with ‘challenging behaviour’ resulting from their dementia. One person told us they had tried a dozen homes before they found one which would accept their loved one.

People had varying experiences of support from social workers during this process. Some reported they had just been given a list of homes and told “It’s your choice’ – but you don’t have the time and the knowledge to do the research to make the choice properly”. Another relative told us that their social worker “was superb, despite working under terrible constraints. She knew what we wanted and why and went out of her way to make sure that, when a place came up at that care home, we knew about it and she was there with the paperwork”.

Some people described the challenges of trying to get continuing healthcare (CHC) funding. One explained that the district nurse had turned up unannounced to make the CHC assessment (‘Mum can’t speak for herself – I would speak for her’) – and, because the care she receives is not being done by a trained nurse, the application was rejected.

People described how it can take months or even years for both residents and relatives to settle into life in a care home. One relative explained how, for a long time after she moved in to a care home, her mother would want to leave with them when they visited and how upsetting they found this.

Some people felt that the support is there but you have to be prepared to accept it, to be open about your financial position, to get to know the care staff and to join support groups. Those relatives who do not feel comfortable doing this (and older people with dementia who do not have a partner or close relative to advocate for them in this way) have a very different experience from those who do.

Those who were getting peer support from others in a similar position, described the benefits they get from this. For example, one woman was planning a trip away for the first time since her husband went into care. She explained:

“ You lot [the support group] have helped a lot with the anxiety about going away.”

Support in finding a home and managing the transition

What makes for a good life in care?

Many of the people we spoke to – even those who were very clear that they were lucky to be in a good care home – missed ‘home’ deeply. One of the questions that arose as we went through the transcripts was: what makes the difference between somewhere feeling like a prison and somewhere feeling like home? It seems to us, there are a number of things here – décor helps, but feeling that you have control and that staff are there to support you to do the things you want to do (not just shoe-horn you into an over-arching regime) seems to matter more.

“All the staff are friendly. The red tape stops it being homely - they’re going to do this, going to do that. Staff could have a bit more time to talk, and do things - there’s so much pressure”.

“When you’re in your own home you can do whatever you want whenever you want. I would ask permission to do certain things here”.

We were also struck by the fact that many of those we met had low expectations – of their lives now as older people and sometimes also of life in a care home. Many told us they ‘hate to grumble’. As the baby boomer generation (which typically has much higher expectations than the war generation) ages and needs residential care, it will be interesting to see what changes this will bring.

“I’ve had a lovely life up to now, so I can’t grumble really.”

“Happy is a big word. I wouldn’t exactly say I am happy really but I think you look at things differently.”

Below we present the six key themes that the care home residents we consulted told us mattered most to them. Even though these individuals were extremely diverse in their attitudes, preferences, personalities and lifestyles, we believe that these things were valued by all and we present them in the collective voice of care home residents. We were struck by how much these themes resonated with the findings of other engagement projects with care home residents and older people with high support needs and/or dementia that we have been involved in or read about (e.g. Bowers et al 2009; Blood 2013, A Bigger Boat 2014, Williamson 2010).

What are the things that are important to care home residents?

Feeling safe is central to leading a good life in a care home. A care home can often make us feel safer than when we lived more independently - we know that we are supported by carers and other staff, that we can get help when we need it, that our money and our belongings are safe and that familiar people are looking out for us.

Some of us unfortunately do not feel safe all of the time. This can be due to knowing how dependent you are on other people for your needs, which can make you feel 'trapped' or 'caged' by the home or staff. It can be hard to trust staff and even families when they are making important decisions about our lives. Sometimes the noise and behaviour of other people living in the home can make you feel unsafe.

Care homes can help us to feel safer by supporting us to be as independent as possible. We want to be able to make choices about the things that are important to us, but also have support from staff when we need it. We don't want to feel that 'being safe' is conditional on getting on well with a member of staff or doing what is expected of us. Seeing lots of people around the home makes some of us feel safe. A calm atmosphere also helps. Knowing that staff treat with confidence the things that we share with them is also important.

Maintaining and developing relationships matters to us now as much as it ever did. We value very highly the contacts and visits we have with our families and friends and our connections with the local community. Although we understand the constraints that make it difficult sometimes for these people to visit us, the loss of these connections is a huge sadness. Positive relationships and friendships within the home (with other residents and with staff) are what makes life good for many of us - although it can sometimes be a challenge to live communally, and a sadness when people leave or die. However, there is often a huge sense of solidarity and comradeship between us residents!

Care homes can help us to maintain existing relationships and develop new ones by welcoming our family and friends and making them feel part of life in the care home. Staff should not underestimate the emotional support they provide us with. Sometimes it is the little things that make all the difference - birthday parties, accompanying us to the shop, sitting at the hairdressers with us, supporting us to vote. Help us to take risks - this is such an essential part of being alive. Introduce us to each other - we have a lot to share and new friendships to make. But make sure there is space for solitariness and quiet times when we need them.

Opportunities to make choices and to have a say in how things are done help us to feel in control and useful. When we move into a care home it can feel as if all our choices have been taken away from us - with lots of other people making decisions on our behalf. It can be hard work to help us to feel confident again about making choices and expressing our views. It can sometimes feel that it is easier for others if we don't speak out, that we might be viewed as a 'troublemaker'. But when we link together that can be better - it's good to be listened to about the things that concern us or changes we would like to see. It builds our confidence. This is our home - it is right that we should have say in our own lives and how things are done here.

Care homes can help us to express choices and to have a say by telling us how we can pass on concerns and ideas to senior staff members. It is good to know where the manager's office is, and to see the manager regularly in the home. Suggestion boxes and residents meetings are good ideas, but it is also important to feel that there is a culture in the home where we can readily say what we feel. Keep asking us for our views and ideas; give us jobs and roles and help us to make choices as much as we can, no matter how small.

Activities that offer meaningful occupation make day to day life much more enjoyable within a care home. We all enjoy doing different things, and we don't all enjoy group activities. Getting out of the home is enjoyable for many of us, but it good to have access to interests and interactions within the home too. Television provides company and is a good way of keeping in touch with life outside the home - but often in communal areas we feel we don't have choice about the programmes and the volume, and it can be difficult to get away from. Many of us enjoy gardens, fresh air, nature and miss these elements of our homes before we moved here. Telephones, newspapers, and computers can help us remain connected with life.

Care homes can help us to participate in meaningful activities by offering an array of opportunities that we can access on an individual basis, as well as within a group. Sometimes we need you to present us with opportunities and encourage us to take part, for example you might suggest that we plant a few bulbs in the garden, or help us to look up something of interest on a computer.

Being supported to go out of the home and make connections with the local community matters to many of us. Some of us go out with our family and friends regularly. But many of us rely on staff to take us out. Organised trips can be very enjoyable, but often it is the smaller, more impromptu trips, that mean the most to us - getting to the hairdressers, going on a little walk, popping to the local shop. Some of us need the support of staff to get out safely and this

can prove difficult when there are not enough staff available. For some of us, our mobility, continence and general health can make it difficult to get out and this affects our confidence. Sometimes though it feels as if we are not 'allowed' to go out, or people think it is too much of a risk.

Care homes can help us to get out by enabling staff to come with us, by focusing on the smaller trips out as well as the organised day trips. Find out the things we want to do, who we want to see, and maybe find other people in the local community who can help us to do these. Invite the local community into the home - especially youngsters!

Remember **it is the little things that make life pleasurable.** **Life** is made up of lots of small moments; it is good for us to continue to experience such moments in our day. Little gestures of kindness can make us feel cared for - a glass of Baileys or a cream cake bought for us; someone taking the time to paint your nails or watch a football match with you. Our photos, jewellery, medals, stories, music are a part of us - help us to stay connected to who we still are.

Care homes can help us to maintain our identity by finding out who we are. Work with our families to create our life stories, support us to still be ourselves.

[What do you think makes for a good life in a care home?]

"If you can be friends with the people next to you - both residents and staff - that's about the staff having the time to be friendly with you. So I think it's mostly about the other people".

We never had anything like this [referring to me and the engagement project when completing profile form] in my day but I suppose it's a good thing – but what difference do you think it will make?

1. Technology – using the potential of computers to promote quality of life

We met a couple of residents who are using personal tablet computers for entertainment and to keep in touch with family members at a distance. We visited a few homes which are starting to use the internet as a way of engaging residents and supporting them to reminisce, have fun and learn new skills.

However, there is plenty of scope and good reason to develop and extend this. Apps and the internet could help those who are very limited in their mobility and also those with dementia, to remember and continue to connect with the wider world, distant friends and relatives and hobbies and passions which are sorely missed.

2. Understanding the Mental Capacity Act and being supported by the wider community to take 'positive risks'

We heard of varying approaches to supporting residents to get out and about from the home. Homes pointed out that it makes a big difference if the resident's family is on board in this decision making. However, managers told us that they sometimes struggle to educate relatives to understand the rights of care home residents in relation to getting out and about. In some cases, they feel that relatives do not support their 'positive risk taking' in this area. There may be uncertainty by some about how to apply the Mental Capacity Act and there can be a fear that the wider health and social care sector would not support them if anything were to go wrong.

Multi-disciplinary risk assessments can help to share the responsibility – we heard, for instance, how occupational therapists can play a valuable role in assessing risks; and how social workers can be updated by email in between review meetings. More dialogue between homes to share their solutions to these issues can help and GCPA can play a key role in facilitating this. Experiences, views and practice examples gathered by this project could inform the development of a leaflet on this topic aimed at relatives.

3. Developing stronger connections between care homes and their local communities

Some homes have good links with their local communities; but many do not. There are a number of ways in which statutory and voluntary agencies, community groups, businesses and members of the public can help to strengthen these links.

Make a point of being a good neighbour to your local care home, whether this is about stopping to say hello to people coming in and out, welcoming residents into your shop/business, or including homes in community activities.

Consider taking your resources and skills into care homes – as a volunteer or as a micro social enterprise. Make sure that care homes are involved in local initiatives such as 'dementia-friendly communities' or the Gloucestershire 'You're Welcome' project. Individuals and groups (in homes and in the wider community) with particular interests could be linked together.

There is plenty of potential to extend volunteer befriending schemes (including intergenerational projects) in care homes and Age UK Gloucester could play a key role in facilitating this.

4. Strengthening and developing new ways of involving residents

There is much transferable learning from the supported housing and care home sector for younger adults here, for example around ways of involving residents in recruitment and selection, menu planning and in making a contribution in the home. There are also opportunities through Innovations in Dementia to develop a collective voice for older people with dementia living in the county's care homes and link this into the emerging national network of DEEP (Dementia Engagement and Empowerment Project).

5 Promoting better understanding and awareness of dementia and support for those affected by it (or afraid of it)

Care home staff need regular training, supervision and best practice dissemination on dementia, including understanding, preventing and responding to signs of distress and 'challenging' behaviours. We heard that there are good free resources available on this within Gloucestershire.

Some extra care housing schemes have done training and awareness sessions with residents as well as staff and this is an idea that could work well in some care homes. This should help to break down barriers between those who have dementia and those who do not, to facilitate mutual support and understanding between residents, and to support those who may be worried about their own memory loss.

6. Supporting the move into care homes (for all concerned)

We heard how important it is for residents to feel as in control of the decision to move and as well-prepared for it as is possible. We were also reminded what a difficult period this can be for partners and family members. Adult social care and health professionals have a key role to play in supporting older people, relatives and care homes to promote the best possible transition. Relatives often struggle to find information about which homes would be suitable for their loved one and which questions they should ask as they look at different homes. Professionals should model an approach of involvement, honesty and transparency with older people during this period and encouraging family members to do the same.

7. Older people with learning disabilities:

We heard how difficult it can be to find the right care and support for older people with learning disabilities who also develop dementia, physical health conditions and nursing care needs, suggesting a need for strategic planning to meet these needs, now and in the future. Stronger links between Older People's and Learning Disability groups and services should help to break down some of the 'silos' here. Those working with older people need to be proactive in making information and services accessible to older people with a Learning Disability.

8. Kick start a wider conversation about care

This project provides a perfect opportunity to amplify the voices of those living in care homes to the general public. The consultation showed how guilt, fear and misconceptions about life in care homes can reduce the quality of life of residents and relatives.

9. Broaden inspections and commissioning frameworks to respond to the voices of older people living in care

Ensure that the themes that emerged from this study as key determinants of quality of life in care from the perspectives of residents themselves are built into commissioning and performance management frameworks. These should, for example, place as much weight on relationships, activities and choice, voice and control as on the more physical aspects of care, nutrition, etc.

10. Developing economies of scale between homes

One or two homes are already pooling resources in relation to activities, and there is more potential to extend these approaches, particularly to small homes which cannot afford to lease a minibus, pay for externally provided activity sessions or employ an activity coordinator.

“Well I wouldn't choose to live here, I'd rather live at home but I can't so that's that”.

“There's no need to be afraid of going into a home like this if it comes to it.”

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We have listed here a selection of practical resources aimed to support and inspire homes and external agencies to offer activities and accessible design for people with dementia:

Alzheimer's Society have produced a factsheet on **physical exercise**, which sets out the key messages from research and suggests exercises for people at different stages of dementia: www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1811

Arts 4 Dementia have compiled research evidence and feedback from participants on the impact which participation in creative activities can have for those with memory loss. www.arts4dementia.org.uk/

The **Alzheimer's Disease International** web site contains ideas, links, resources and video clips on a range of innovative activities and creative approaches from around the world www.alz.co.uk/icanill/library/professional-carers/activities.

The **Alive!** Team have drawn together their recommended iPad apps for people with dementia, together with research evidence at www.memoryappsfordementia.org.uk/

NIACE has recently produced **guidance for local authorities** on how to promote learning opportunities for older people in care: www.shop.niace.org.uk/media/catalog/product/t/h/thoughts_for_local_authorities-final.pdf

The **Life Story Network** web site has a range of resources to support reminiscence at www.lifestorynetwork.org.uk/

National Museums Liverpool has developed the **My House of Memories app**, which allows you to explore objects from the past and share memories together. It can be downloaded for free from: www.liverpoolmuseums.org.uk/learning/projects/house-of-memories/my-house-of-memories-app.aspx

These one-page factsheets are from the **American 'Best Friends' approach**, which argues that 'activities' are everywhere (many can be done in 30 seconds!) and the emphasis is on connection rather than 'doing something'.

A Best Friends approach to activities: www.bestfriendsapproach.com/Downloads/Activities.pdf

30 (more) things to do in 30 seconds or less: www.bestfriendsapproach.com/Downloads/Thirty%20Things.pdf

Tips for hiring staff with knack: www.bestfriendsapproach.com/Downloads/Staff_Knack.pdf

Ten ways to change culture in long term care: www.bestfriendsapproach.com/Downloads/Culture.pdf

A '**circles of support**' approach involves bringing together a group of people (this can be as small as just two people and might include family, friends and paid staff) to help a person identify what they would like to do or change in their life and then supporting them to make this happen. The person-centred 'planning questions' and recording tool are available at www.ndti.org.uk/major-projects/current/circles-of-support-for-people-with-dementia/ along with individual stories and an overview of early findings.

The **Dementia Green Care Handbook** gives lots of information about how to create and use outdoor spaces successfully for people with dementia www.housinglin.org.uk/_library/Resources/Housing/OtherOrganisation/Dementia_Green_Care_Handbook.pdf

The **Virtual Care Home** site allows you to click on features within photos of different rooms to show best practice in interior design for people with dementia. www.dementia.stir.ac.uk/design/virtual-environments/virtual-care-home

This short film from SCIE sets out some of the ways in which interior design can promote independence and calm for people with dementia in a care home. www.scie.org.uk/socialcaretv/video-player.asp?v=dementiaenvironmentinacarehome

Appendices

Listening to the voices of older people in care homes

We want to be sure that you feel happy to take part in this project.

Please read the following statements:

- ▶ I have read and understood the information sheet about the project
- ▶ I am happy to talk with Imogen about my views
- ▶ I know that this information will be written down or tape recorded.
- ▶ I know that I can decide to stop talking at any point. I can ask that my views not be included in the project report.
- ▶ I know that my name will not be used in any written reports

I agree to take part in this project

I don't agree to take part in this project



Imogen Blood

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Contact details
of the interviewer:



We are Rachael, Imogen, Jenny and Alise

from Imogen Blood & Associates and Innovations in Dementia.

We have been asked by Age UK Gloucestershire to meet with older people living in residential and nursing homes in Gloucestershire.

We want to hear what **you** think makes a **good life in a care home** and whether there is more the wider community could do to support this. This will help the council, the Police, Age UK and care homes understand how they can work together to help make residents feel **happy, safe and secure**.

What's it like living here?

What do you like doing?
Are there things you would like to do more of?

How do you stay in touch with the outside world?

Do you get a say in how things are run in your home?

We are coming to visit your home on [xxxxx](#) and would like to hear your views. We treat everything we are told in strict confidence and you do not have to speak to us if you don't want to.

If you want to find out more about the project, please e-mail Imogen on imogen@imogenblood.co.uk or call [Rachael](tel:01392420076) on 01392 420076.

Questions for use in 1-1s with care home residents

This is the topic guide for use when we get the opportunity to do a more in-depth, private conversation with an individual.

Begin by talking through the consent flyer. Make it clear that you are either going to write notes or switch on your recorder (this gives a clear visual prompt which may also be a key part of establishing consent – if people question either during the discussion, it gives an opportunity to pause and re-explain)

1. Who do you see regularly?

Use the 'people' images if this is helpful for people – one approach would be to lay them out in a circle, putting the people they see most regularly in the centre and those they see less frequently on the outer ring(s).

Allow space for people to talk about their relationships with these people, prompting as appropriate.

- ▶ Who would you like to see more of?

2. How do you keep in touch with the outside world?

Prompts:

- ▶ TV, radio, newspapers, newsletters, magazine (do they get a choice of what's on/ available?)
- ▶ Phone (do they have their own mobile/ phone in room – how did this come about – can they use it independently – who do they call/ when/ how often?)
- ▶ Internet?
- ▶ People coming to visit?

3. Do you get out of the home much?

Prompts:

- ▶ Do you enjoy this – where do you go?
- ▶ Would you like to get out more – what stops you?

4. What sort of things do you like to do?

We have a set of 'activity' images which can be spread out/ flicked through if people find this helpful to remember things they do now/ liked to do in the past/ what they miss doing. (Some people may have lost motivation/ memory so that it is hard even to think what they might do) Also hope to prompt people here to talk about attitudes to risk and barriers (e.g. around being allowed out on your own/ doing something daring) – e.g. daughter/ doctor/ home manager says they can't do something anymore – do they agree? (or it could be the other way around of course, with others encouraging them to do things but them not wanting to – explore why...). Do they feel they have a say in what they do?

5. What's it like living here?

(For people with more severe cognitive impairments, this question could be accompanied by a gesture of pointing around.....)

Use the emoticons as a prompt where appropriate.

Depending on the sort of response here/ general perception of how the person is/ cognitive and communication level and length of interview so far, use some or all of the following prompts:

- ▶ Do you feel happy?
- ▶ What would help you feel happier?
- ▶ Do you feel safe and secure?
- ▶ What would help you feel safer/ more secure?

6. Do you have a say in how the home is run?

We might not get this far (in terms of time, energy, cognition....) with some people but, if we do, this is a good point to re-explain why we are doing this.....

We have been asked to do this project by the council, the Police, Age UK and care homes in Gloucestershire. These organisations want to understand whether there is anything else they could do to help make residents feel happy, safe and secure.

What could someone living here do if.....

- ▶ ...they didn't like the food or wanted to eat something that wasn't on the menu?
- ▶ ...they didn't get on with a member of staff
- ▶ ...they didn't agree with their doctor or social worker?
- ▶ ...they had concerns about another resident?

Thank them and remind them what we will do with the information – not tell anyone their name, store safely, etc, etc.

Complete demographic form – ask permission to check any information with care home manager if they can't remember or are too tired to complete it.





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Care Home Whispers

Listening to the Voices of Older People
living in Gloucestershire Care Homes

Final Report | February 2015