



care
inspectorate

Findings from consultation
with family carers of people
who live in care homes – Au-
gust-October 2024

Meaningful Connection

Findings from
consultation with
family carers of
people who live in
care homes

August-October 2024



HAPPY TO TRANSLATE

Executive Summary

Consultation was carried out with family carers of people experiencing care in adult and older people's care homes in Scotland to help ensure we are hearing their voices and to widen knowledge of their experiences and views.

The key findings were as follows:

- Respondents described spending significant time with their relative or friend and carrying out a variety of roles which supported their emotional, mental and physical health and wellbeing.
- Most survey respondents felt welcome in the care home. They highly valued a friendly, welcoming staff attitude, with many referring to the importance of a smile and personal greeting, a hospitable atmosphere, and freely offered information.
- Most respondents could visit the home freely, but some described experiencing restrictions, particularly around mealtimes.
- Some respondents described difficulties accessing the home. However, over half of respondents had been given the door entry code.
- Many respondents referred to the importance of open, transparent communication, but experiences of this were mixed.
- A number of respondents said they appreciated or would like the opportunity to stay for a meal or join in activities within the home.
- While most felt confident that the care home would handle any concerns or complaints they raised appropriately, some respondents recounted situations where this had not occurred.

Introduction

The Meaningful Connection, Visiting and Anne's Law Project was set up with funding from the Scottish Government to support and promote the importance of all types of meaningful connection for people who live in adult and older people's care homes, as well as to help prepare the sector for the implementation of Anne's Law. The work of the project is based on the core principle that experiencing connection which is meaningful and person-centred is essential to everyone's health, wellbeing and personhood, and forms part of human rights.

[Research](#) shows that while the roles of family carers may change when a loved one moves into a care home, their involvement is no less important. Many family carers continue to play a vital role in the lives of people in care homes, extending well beyond simply being a visitor. Their involvement as valued partners in care supports the emotional, mental, social and physical wellbeing of their loved ones, helping to maintain personhood and belonging, and acting as guardians of identity and dignity.

The purpose of this consultation was to widen our knowledge of the experiences and views of family carers, particularly in terms of what factors promote or undermine inclusion and partnership. This follows our [previous engagement](#) with people living in care homes, their families, friends, and staff.

Terminology

For the purpose of this report, we have used the term 'family carers' to refer to immediate and extended family, friends and other close contacts who play ongoing and vital roles in the lives of people who live in care homes. The term 'people experiencing care' has been used to refer to people who live in care homes.

Methodology

Responses were gathered by Microsoft Forms, circulated over eight weeks via Care Inspectorate mailings, social media, care home relatives groups, and the Meaningful Connection Project's mailing list. The form was designed to gather both quantitative and qualitative data. Care home managers were requested to distribute the form among family carers, and also to inform people who may not wish or be able to complete the form

digitally, that they were welcome to get in touch by phone or email to share their views and experiences.

The form and contact details were disseminated as widely as possible in an attempt to reach family carers through various means. However, there was some reliance on care home managers to distribute them, and this may have inclined the results to some extent towards better-performing services.

A total of 191 responses were received. The vast majority (96%) of respondents identified themselves as family members. Of these, 71% were a daughter or son, 6% were spouses, 5% parents, 3% siblings, and the remainder mainly grandchildren, nieces, nephews or cousins. 84% of respondents said they had legal powers to make decisions on their relative or friend's behalf, i.e. Power of Attorney or Welfare Guardianship.

The responses were collated and evaluated using a framework analysis approach, categorising the data into key themes.

We would like to thank everyone who responded to share their views and experiences. Many of their quotes have been used throughout this report. All quotes have been anonymised.

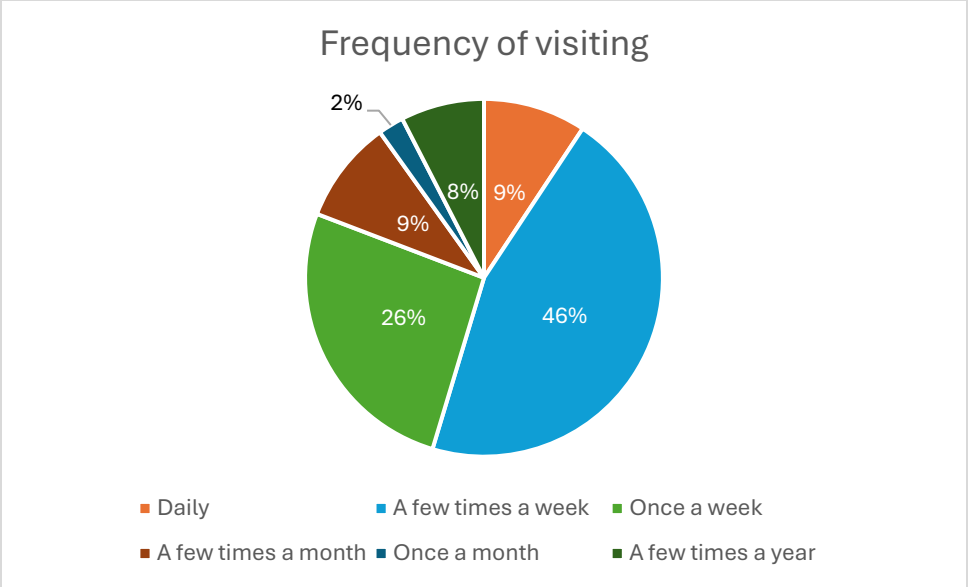
Themes

The following key themes were identified:

- Roles and involvement of family carers
- Feeling welcome
- Being included
- Raising concerns

Roles and involvement of family carers

Over 80% of respondents visited their relative or friend at least once a week, with 46% visiting a few times a week and 9% visiting daily. This indicates that a large majority of respondents (81%) were frequent visitors who continued to play important roles in the lives of people experiencing care.



People were asked to identify how they supported their relative or friend. The majority described providing company and social contact (86%), being an advocate (e.g. liaising with care home staff) (84%), providing emotional support (78%), and assisting with practical affairs such as financial management or arranging/attending appointments (77%). A total of 42% of people described supporting their relative or friend with getting out and about, and 19% supported with day-to-day care (e.g. personal care, help with eating and drinking).

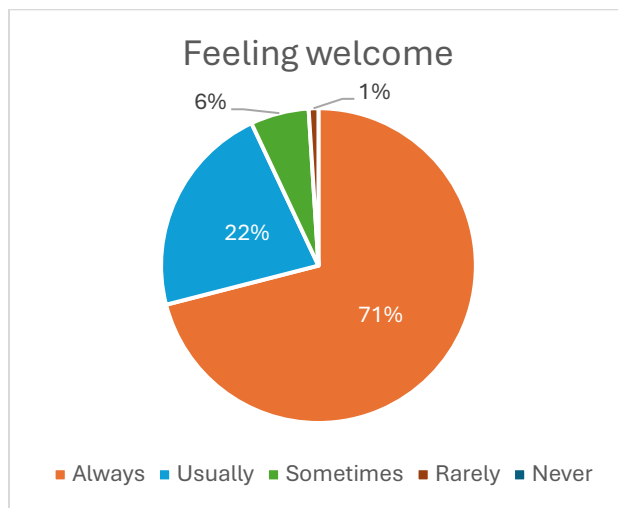
This reflects previous findings regarding the important roles of family carers, which include social and emotional support, advocacy and monitoring, and involvement in direct care. All of these contribute to the emotional, physical and mental health and wellbeing of the person experiencing care. Family carer support provides a valuable link to life before and beyond the care home, supporting identity, continuity and self-worth.

Many family carers also play a role in the life of the care home as a whole, contributing to the community within the home. This can include volunteering to help support activities, events or outings, involvement in fund-raising, or being part of relatives' groups. Some family carers have formed supportive links with other relatives or residents.

Feeling welcome

Inclusion is facilitated when family carers feel welcomed into the home. Respondents were asked to what extent they felt welcome when visiting the care home, and what the home did, or could do, to help them feel welcome.

It was good to see that 71% of respondents said they always felt welcome when visiting the care home, with a further 22% saying they usually did. 6% said they sometimes felt welcome, and only 1% answered rarely. No respondents said they never felt welcome.



Through analysis of the information provided, key themes emerged in terms of the factors which contributed to feeling welcome. These are discussed below.

Staff approach

More than half of respondents referred to the importance of staff members' approach as the most important factor in creating a welcoming atmosphere, emphasising the importance of a smile and a friendly greeting.

“I have always been made to feel welcome. Staff are friendly and even if busy will stop to say hello.”

“Some staff may not appreciate how much a simple smile or word of greeting can go towards making you feel welcome and valued within the home.”

“Wherever you go in the care home you are always met with smiles. And although I can see that they are sometimes very busy with a specific issue, they are always smiling. It probably helps when my dog visits with me!”

People often said they appreciated when staff knew them and their relative/friend well and appeared both informative and interested, providing updates on how their relative or friend had been and on the home in general.

“Staff always speak kindly to me, call me by my first name and update me on how my husband is. They take an interest in me and our family.”

“They chat and welcome me on a friend-to-friend basis and keep me well informed on my mum’s situation and what’s going on.”

“All staff are very welcoming and take time to chat, when we are having a coffee with Mum they will often come across and chat to us all.”

Many said they appreciated practical things like being offered tea, coffee, or to stay for a meal.

“The staff, from manager to domestics, usually say hi and use my name and smile if they are around. They ask how I am and tell me how my relative is. They offer me cups of tea and sometimes ask if I want a meal if I’m there at that time. Sometimes there’s nobody around and it would be nice to have a member of staff available every time you go in or out. I know it’s not possible.”

“They say hello and offer tea and home baking. They often offer lunch too.”

A small number of family carers, however, mentioned having the perception that they were unwelcome or causing a nuisance to staff.

“Generally I am an inconvenience.”

“I sometimes feel like a nuisance when I want to visit. I work full time so it can be difficult.”

Some people mentioned continuity of staff being an issue which could affect their experience of feeling welcomed and acknowledged.

“As the staff change a lot, they don’t tend to know who I’m there to visit.”

“There’s quite a few new staff and agency at times and they don’t always give you eye contact.”

Some respondents said they would like more information or choices to support their visit.

“I’d like them to ask where it would be most convenient to spend time with my friend. I’d prefer her own room or the dining room, but we usually have to sit in the sitting room with a loud TV and other residents.”

“I’d like something like a welcome pack that gives you information, like about where you can go and what you can do. Nobody really tells you.”

Several respondents mentioned the importance of a welcoming physical environment.

“The entrance to the home always has flowers with a card to say which resident has chosen them, there is a blackboard with handwritten details of the meal menu. There are couches to sit on and lots of recent photos of the residents at events, on outings and involved in activities.... There are always sounds of people singing and laughing.”

“The care home entrance and corridors are welcoming - bright, open, airy, and decorated (flowers, notices, etc).”

Getting access

Being able to enter the care home easily without unnecessary delay was important to many people, and several respondents mentioned difficulties in gaining access as a significant issue for them which did not contribute to feeling welcome

“Quite often I wait a lengthy time for entry when there are people sitting in the office and ignoring the buzzer. I have often had to telephone for entry!”

“The doorbell on weekdays is answered by the receptionist. However, at weekends it is the staff that answer the door and you have no idea of when you will be allowed in.”

“You depend on staff to let you in, which is not great in winter if you have to wait outside.”

However, 57% of respondents said they had, as regular visitors, been provided with the door codes to be able to access the care home easily, and found this contributed to a positive experience.

“Regular visitors have the code to the front door and are always welcome.”

“We often used to have to wait outside, but now we have the door code which is much better.”

Several people who did not have the codes expressed that they would find this helpful.

“Having access to the entry/exit code would make it much easier.”

“The only drawback for me is that you have to be let in and out because only staff know the code for the doors.”

“They should give door codes.”

Freedom to visit without restrictions

It is important that people can see their [visitors](#) freely, and other than in exceptional circumstances there should be no restrictions on visiting the care home and no booking systems should be in place. It was reassuring to see that 91% of respondents answered “Yes” to the statement “I am able to visit freely and without restriction”.

Some people, however, said they did experience restrictions on when they were able to spend time in the home with their relative or friend. This was particularly, though not exclusively, the case around mealtimes.

“Restrictions exist around breakfast, lunch and tea. And no visiting before 10.30am.”

“Lately I’ve been reminded at the door that it’s mealtime and there’s restrictions... I am puzzled by this as my relative eats in her own room and often needs help to eat her food.”

“Too many restrictions, e.g. appointments only.”

“The home restricts visiting times. In theory I can visit when I want to, but in practice it's discouraged outside the hours of 10.00-12.00 and 13.00-16.00.”

For many people, these limitations impacted on the time they could spend with their relative or friend.

“They have restrictions around mealtimes – breakfast, lunch and dinner. As I travel some distance to see my relative it can make it a very short visit.”

“It means for three hours in the day I can’t visit my mum.”

Several people expressed concerns about the restrictions which existed for care homes during the Covid-19 pandemic and expressed the hope that this would never happen again in the future.

“The vital role played by a daughter, son, spouse etc must be formally recognised within Anne's Law. It is unbearable to think that I could be forbidden from seeing

mum if there was another pandemic and yet with infection prevention and control precautions the care staff would all have access to her room.”

“It is imperative that family members are always allowed into care homes and are never locked out again as in 2020/2021. This hastened the progress of my mum’s dementia and took its toll on our family.”

Being included

When family carers are valued and included as partners in care, there are often numerous benefits for the person experiencing care, the family carer, and the care home as a whole.

However, although a large majority of respondents (84%) had legal powers to act on behalf of their relative or friend, people described varying levels of inclusion.

“Every visit feels like visiting my mum in a home environment with extended family.”

“It sometimes seems like the staff just think I’m a nuisance interrupting their work.”

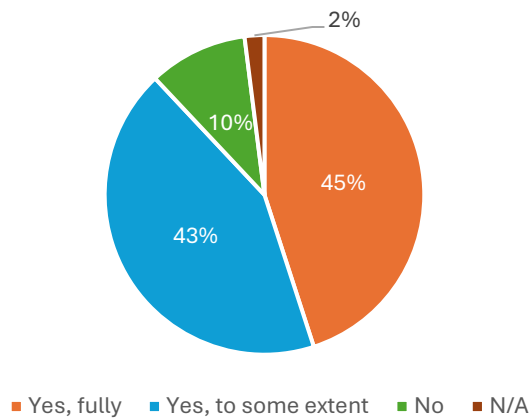
Some of the factors which foster inclusion are discussed below.

Inclusion in personal planning

It is important that family carers are, where appropriate, fully involved in personal planning (care planning) and reviews. They can provide vital information about the person's life, interests, values and preferences which support person-centred and led care, and are often involved on a day-to-day basis in providing support. Their deep personal knowledge of the person experiencing care often means they are well placed to pick up on small changes in health or wellbeing which staff may not always notice. They can act as advocates on behalf of their relative or friend, passing on information or concerns to staff.

Most survey respondents said they had been involved fully (45%) or partly (43%) in personal planning. 10% had had no involvement and 2% said it was not applicable (i.e. they would not expect to be involved due to their role).

I have been involved in and know the content of my relative/friend's personal plan



"I've been fully involved in my relative's care plan from day one. It's really important, because though the staff know her well, I'm the one that knows her the best and able to tell them all the little things that make a difference."

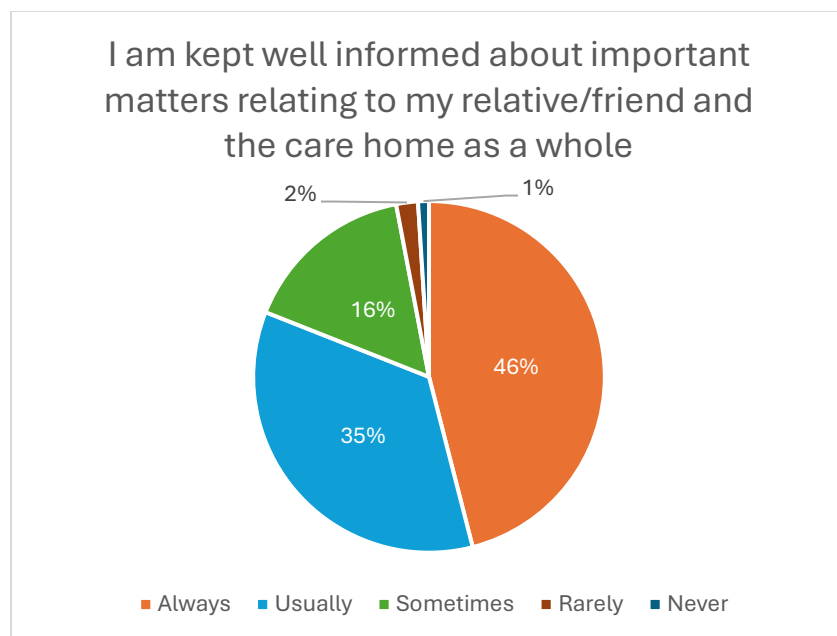
"I've given them a lot of information about his likes and dislikes etc. but I'm not convinced anybody actually looks at it. Reviews only seem to happen sporadically."

Effective communication

Effective communication helps keep family carers included and builds trust. Many respondents described the importance of regular, open and transparent communication, both about issues affecting their loved ones and the home as a whole.

"My relative is very happy and receives mainly excellent care. I feel that at times we have been let down by a lack of communication about matters of varying importance, sometimes minor but still of importance to us as a family to know about, and on some occasions more serious. The importance of good communication should never be underestimated as when a relative is not able to give exact details/ pass on information coherently we should feel confident that staff will keep us fully informed."

Most respondents (81%) said they were always or usually kept well-informed, with a minority stating sometimes (16%), rarely (2%), or never (1%).



People described differing experiences around effective communication. Honest, transparent and freely offered communication was highly valued.

“All staff are always welcoming and let me know how Mum is and if there’s anything they are worried about.”

“They are always willing to discuss my mother’s situation. They are always very open about how the home is being run and any current problems.”

However, not everyone experienced positive and proactive communication.

“I can be there 2-3 hours in mum’s room and no one checks everything is OK. No one gives you an update unless you ask.”

“I occasionally get a call from one member of staff who has been there a long time. Other than that, they only get in touch about the financial stuff.”

Some expressed that communication was good in some areas, but not in others.

“I am kept well-informed about my relative's health matters (e.g. falls and medication changes) but not at all about her activities or the care home as a whole.”

Some people described giving information to staff which supported person-centred and led care, but that this was not always relayed to other staff.

“Sometimes communication isn’t passed on about residents to other staff, but I know they’re busy. Simple things like my mum likes a certain amount of sugar in her tea which makes her drink more. I often have to repeat this to them or add sugar which I bring in myself.”

“The internal administration of the care home could be improved as on several occasions, unit ‘frontline’ staff request information already supplied to the central admin/office.”

“Communication between staff on my mum’s unit is not always satisfactory and I feel sometimes they are under enormous pressure because of the number of carers to residents.”

Several respondents offered suggestions for how communication could be improved.

“I would like to see more active and in-depth conversations by a key worker on a regular basis with feedback regularly from that key worker to myself... Care is very task-oriented and should be more person-centred with concern for the resident’s anxieties and worries.”

“For family overseas, I feel it would be really beneficial and comforting to receive a personal report on a weekly or fortnightly basis.”

Respondents also mentioned the importance of being kept informed about changes or issues within the home.

“Apart from occasional relatives’ meetings, there is not much information given. A regular newsletter would be good.”

“They should introduce new members of staff and make sure staff have name badges.”

For some people, relatives’ meetings were a helpful source of information and an opportunity to discuss issues. However, this was not always effective.

“As I was unable to attend a planned relatives’ meeting, I raised a number of concerns with the manager [for discussion at the meeting]. On viewing the minutes of the meeting, none of the concerns had been discussed.”

Inclusion in day-to-day activities

Opportunities to join in communal activities or to share a meal with their relative or friend were valued by many people and helped feelings of inclusion. Although not all family

carers are able or want to do this, for some this can make the visit more enjoyable and meaningful. Events such as coffee mornings or other occasions can also contribute to inclusion and building a sense of community within the home.

“I can join in with any activities that are going on.”

“My relative doesn’t communicate so much verbally but is always included in activities and I can join in if I am there at the time.”

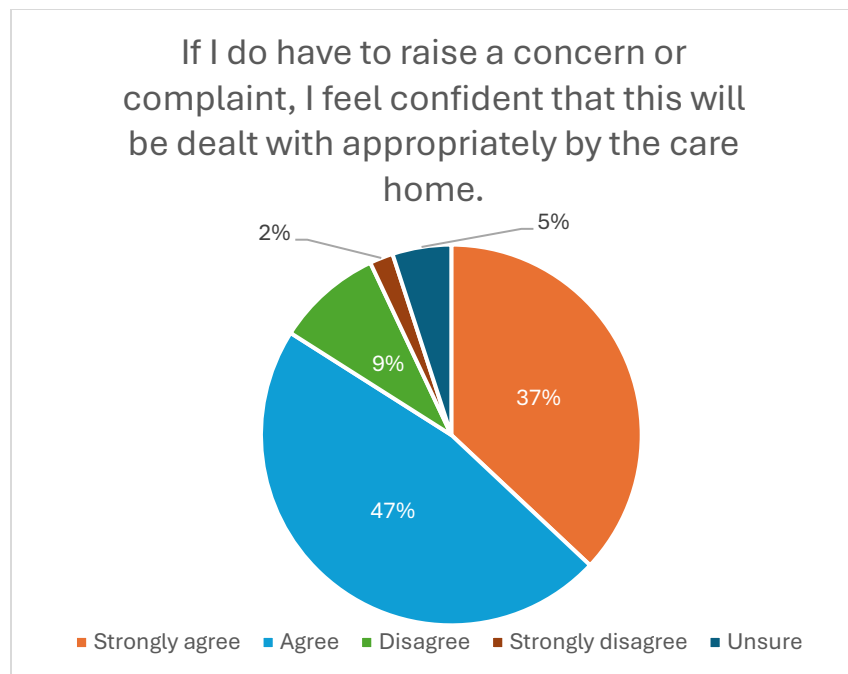
“If I’m there at a mealtime they often ask if I want to stay for the meal.”

“I’d like the opportunity to be able to stay for a meal with my relative – I’d be happy to pay for this.”

Raising concerns

The ability to freely raise any concerns or complaints, and feel confident that these will be taken seriously and dealt with appropriately, is essential to building trust and partnerships and contributes to high-quality care. A positive approach to complaints is one where feedback, whether positive or negative, is welcomed and encouraged, and concerns are seen as an opportunity for improvement.

The vast majority (98%) of respondents said they knew how to raise any concerns they had. Over 80% felt confident that these would be dealt with appropriately, with 37% saying strongly agree and 47% saying Agree. However, 9% disagreed, 2% strongly disagreed, and 5% were unsure.



While many respondents expressed confidence that any concerns had been, or would be dealt with appropriately, some had had less positive experiences.

“On a near daily basis, I have mentioned to seniors some concerns about my relative’s care and have not had responses which have been helpful. Also, I have been promised that I will receive a call later on the day... it hasn’t come!”

“I have had to raise concerns with the Care Inspectorate.”

For some, fear of adverse consequences deterred them from raising concerns.

“I feel like I have good relationships with the staff and they are very good on the whole, but that puts me off saying anything in case it turns them against me or even worse, my relative.”

Some people explained that although concerns would be dealt with at the time, this did not seem to stop those or other concerns from occurring in the future.

“I have raised concerns but I’m not sure it has made a difference in the long term. Sometimes it’s soul-destroying hearing the same thing is happening.”

“There is an ongoing problem where if we raise a concern the staff will deal with the problem; but they do not seem to be able to prevent problems occurring or anticipating problems. Too many things seem to take them by surprise.”

Some people felt that they had been treated less favourably as a result of raising concerns.

“Since raising concerns, staff ignore me.”

Conclusion and Recommendations

The responses illustrated how profoundly many family carers are involved in the lives of their loved ones who experience care in care homes, and the variety of important roles which they carry out, making a vital contribution to the wellbeing of their relative or friend. They provide social and emotional support, act as advocates, provide essential information to support person-centred care, support continuity and connection with the world outside the care home, and often support with direct care.

The responses emphasise the importance to family carers of being able to visit freely, feeling welcome, being included, and being able to raise concerns confidently. While the majority of people who replied to the survey had positive experiences, there were concerns for some. These were most commonly around ease of access to the home, visiting restrictions around mealtimes or at other times, communication both internally and externally, and the ability to raise concerns and have these appropriately responded to.

Providers should consult regularly with family carers around these issues, and act upon the findings, in order to ensure that wherever possible family carers are welcomed, valued and included as equal partners in care.

Things to consider

- How can we ensure family carers are welcome in the home, including being able to easily access it, and that they have information to support their visit?
- Is visiting unrestricted (except in exceptional circumstances)?
- Do all staff understand and facilitate the importance of family inclusion and building positive relationships?
- Are complaints and concerns treated as a positive opportunity for improvement and responded to appropriately?
- Is family involvement encouraged and welcomed, including in day-to-day care if this is what people want?
- How do we ensure communication is effective, both externally and internally?

Resources

[Care home visiting factsheet](#)

[Information and resources on meaningful connection](#)

[Meaningful connection self-evaluation tool](#)

[NAPA Guide to Meaningful Visits](#)

[Come On In leaflet](#)

[Open Badges](#)

[Personal planning guidance](#)

[Report on engagement visits to care homes](#)

[Poster](#)

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