

Supporting shared decision making in care homes



My Home Life England is part of an evidence-based, research informed international initiative focused on supporting quality of life for people who live, die, work in and visit care homes. We are hosted by City, University of London.

My home life[®]
England

Introduction

This guide focuses on how to support shared decision making within a care home. It has been co-created with a group of people who work in care homes across England. They have been very generous in sharing their knowledge, expertise and perspectives.



About shared decision making

Shared decision making is an inclusive process where a person works alongside another individual or individuals to reach a decision.

People living in care homes have the right to be included in decisions, including those about their care. Shared decision making should also include other people working in and connected to care homes, including team members and other employees, visitors including unpaid carers and other colleagues within health and social care.

Shared decision making:

- Supports people, including people living in care homes, to make informed choices and decisions, including those they feel are right for them.
- Ensures people understand all possible outcomes of a situation.
- Allows people to choose to what extent they would like to be involved in decision making. Some may not wish to take an active role, but importantly they have still had the opportunity to do so.
- Is grounded in how a care home develops, involving all people who live, work and visit the home (the home's culture or ethos) as well as individual and personal decisions.

Shared decision making is one of the best practice themes that supports My Home Life's work to enhance and develop quality of life in care. Fairness, respect, equality, diversity and autonomy (the FREDA principles) and a human rights-based approach to care shine through all the case studies, practice examples and ideas featured in this guide.

Whilst many of the examples and ideas in this guide focus on great care and working with people on an individual basis, everyone involved has also talked about the importance of 'care-free' conversations between people who live, work in and visit a home. These conversations are not about care but about other aspects of daily life, discussing what's important together – for example meal choices, recruitment of staff, daily activities, decoration of the care home and more.

How to use this guide

In this guide you will find:

- A shared decision making poster to print off and use around the care home (it has a QR code which links to this full guide when scanned).
- Case studies, positive practice thoughts and ideas to help support and develop discussions about shared decision making.
- Links to My Home Life tools and ideas that can support people in thinking about shared decision making.
- More detailed information including some of the legal and regulatory frameworks that influence shared decision making.
- A spoken version of the guide can be accessed [here](#) or by scanning this QR code.



You might find it helpful to:

- Put the poster up in the care home, for example in a lift, office, or on a notice board. This might prompt an open discussion between people who live in the home and the team, between staff in a supervision, or between a family member, close friend and someone working in the home.
- Use the case studies and practice examples with people. This could be in team meetings, individual meetings with people who live in the home, when developing a support plan with someone or in discussion with a family member. Asking open questions, being curious and listening well to each other will help to support shared decision making and will also be important in the 'care-free' conversations every day about living together in the home.
- Include this guide as part of a new team member's induction.
- Use some of the ideas and positive practice examples to support a detailed conversation with the wider team and other individuals involved in someone's support and care.

For your information

In this guide we use the terms ‘people who live in a care home’ and ‘someone’s support circle’. While many people who live in a care home have a strong and supportive relationship with an unpaid carer or family member, others may have different people in their support circle, such as a long-standing partner, a friend, a community advocate or an attorney through lasting power of attorney. Each person’s circumstances will be unique in terms of who is close to them, who is interested in what is happening in their lives and how these people are involved.

People from wider health and care teams also need to be considered in the way shared decision making is thought about and made real. Sometimes people who are not working with someone 24 hours a day may need more time to help understand how a decision has been made. Others might also have a formal role (for example an attorney) that requires their involvement in decision making.

Supporting people who live in the care home

Every day there will be many opportunities for people living in care homes to make decisions, communicate their preferences and demonstrate their interests and talents. These opportunities will range from basic decisions to more complex ones, including those that might be considered 'unwise' by others.

Empowering people to retain their autonomy and be involved in decisions, reinforces a sense of purpose and value and can help someone feel in control. It creates a sense of connection and reciprocity and helps strengthen the relationships and trust formed between people living in a care home and those who care for them. It also promotes equality, inclusion and respect, as well as contributing to a positive home culture.

Some people may feel very able to participate in decision making and others might need further support in order to be involved in an appropriate way.

The following practice examples show shared decision making in action:

Kippers for breakfast

Rod has always loved eating kippers for breakfast. He lives in a care home and recently has started to have more difficulty swallowing. Staff were concerned about Rod's safety and his risk of choking if he continued to eat kippers, as well as any potential repercussions for them if he did choke. However, they also recognised that eating kippers was positive for Rod's quality of life.



Zoe, manager at the home, arranged an urgent capacity assessment through the DoLS team as Rod's current care plan did not correspond to his capacity. Zoe also did a risk assessment with Rod and had a chat with him about the risks associated with eating kippers.

Rod confirmed that he understood that eating kippers may cause him to choke, but said he wanted to continue eating them. Zoe made a note of Rod's wishes in his care plan, reassured staff that supporting his decision was the right thing to do and asked them to be aware of the situation at breakfast. Everyone working in the home respects Rod's decision. All monthly reviews are signed off by him and he continues to eat kippers for breakfast.

Smoking or non-smoking?

Sheila has Chronic Obstructive Pulmonary Disease (COPD) and is on oxygen. Before moving to live in her care home, Sheila smoked for 55 years. Shortly after moving in, Sheila ordered cigarettes to the home. Staff were very concerned about the impact smoking would have on Sheila's health.



Despite the health risk, Home Manager Wendy recognised how important the choice to smoke was to Sheila. Sheila told Wendy it was the activity that brought her the most joy. Wendy explained all the risks of smoking to Sheila, and the GP did the same. Wendy also explained that if Sheila was to go outside for a smoke, she couldn't have oxygen at the same time and this could possibly be a fatal risk. Sheila confirmed she understood the increased risk that smoking posed to her health, but still wanted to smoke because of the happiness it brought her.

Staff now support Sheila to smoke, even if they personally disagree with her decision, and Sheila chooses the amount of cigarettes she has each day. All the details are outlined in Sheila's care plan and her COPD specialist and GP have been informed.

Positive practice thoughts for supporting people living in care homes in shared decision making

- ✓ **Positive risk assessment:** Do we understand the risks involved and have we considered together possible ways to mitigate these risks? Have we explored how a person could do something safely?
- ✓ **Peoples' preferences:** Are we staying curious about what people prefer today rather than yesterday? Have we asked them today about their preferences?
- ✓ **Peoples' stories and lives:** Have we thought about peoples' past and lives when making Best Interest decisions for someone who does not have capacity to make a decision themselves?
- ✓ **Other perspectives and 'unwise decisions':** Have we considered other perspectives, especially regarding a decision we personally would make differently or a decision we might think is 'unwise'?
- ✓ **Capacity:** Have we collaborated to help someone make their own decisions as much as possible? Have we still included any people with Power of Attorney for financial decisions in other conversations around lifestyle decisions?
- ✓ **Everyday decisions:** How do we involve people who live in the home in everyday decisions about living together? Are we involving them in changes that are happening in the home? Do we have a way of regularly checking out what's working for people and asking what changes they might want to see?
- ✓ **Celebrating shared decision making:** How can we find out what went well in shared decision making and celebrate it? Have we thought about what could make things even better?



Supporting team members working in a care home

Every day in care homes teams do a brilliant job delivering person-led care and listening to and responding to a person's needs and desires. Shared decision making is a natural part of this process. Supporting a person to make decisions, retain their autonomy and have their voice heard is an integral part of quality care and it promotes quality of life. It also helps to create equal relationships between people living and working in a home, rather than hierarchies, and it promotes respect and understanding.

Just as people working in the home involve those living there in decisions, staff should also feel that they themselves have a place in decision making within their workplace and that other team members or senior leaders involve them in appropriate decisions.

The **Caring Conversations** framework can be a helpful way of approaching the topic of shared decision making in care homes. The framework suggests that in order to deliver compassionate and dignified care, people need to: Be Courageous, Celebrate, Connect Emotionally, Be Curious, Collaborate, Consider Other Perspectives and Compromise.

This framework helps team members to explore values and different points of view, acknowledge and express emotion without dispute or judgement, and it encourages better listening. It also supports a different attitude to risk-taking and devising new approaches to problems, ultimately enhancing quality of life.



Dewar B and Nolan M (2013) Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting, *International Journal of Nursing Studies*, 50(9):1247-58.



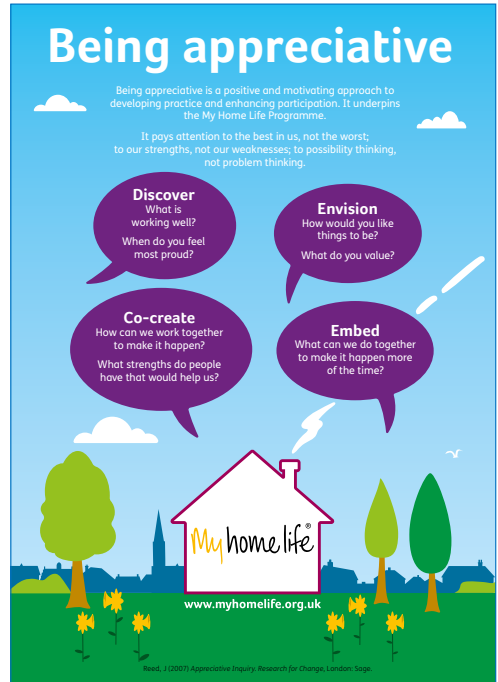
Practice point – How could you use this framework in your own practice to support team members to think about and participate in shared decision making?

Being appreciative

Being appreciative is a positive and motivating approach to developing and improving practice and enhancing participation.

It pays attention to the best in us, not the worst; to our strengths, not our weaknesses; to possibility thinking, not problem thinking. It focuses on doing more of what is already working, rather than focusing on fixing problems.

The four phases of this approach are: Discover, Envision, Co-create and Embed.



Reed, J (2007) Appreciative Inquiry. Research for Change, London: Sage

Appreciative and reflective questions teams could consider

- What is working well and how could you make it even better?
- How could things work differently?
- How do you feel about this situation?
- How would you like things to be?
- What small step might help to improve the situation?
- What would you and others gain if something was carried out differently?
- How might you support someone to have their voice heard?
- What can you do to make someone feel supported?
- How might you feel if you were in this situation?

Positive practice thoughts for team members working in the care home

✓ **Understanding:** How confident do team members feel to recognise shared decision making when it happens? What potential might there be to use team meetings and supervisions as opportunities to talk about staff experiences or stories on shared decision making? What is working well regarding shared decision making and what could happen more often?

✓ **Conversations about shared decision making:** What opportunities are there to talk openly about ideas and thoughts on shared decision making and learn together? How could team members be encouraged to consider other perspectives and compromise when it comes to shared decision making?



✓ **Care plans:** Care plans are a record of care and should give the team confidence that they are supporting a person to live on their chosen terms. What questions might staff have regarding the purpose of care plans and their role in risk-taking agreements? Is there something you could do to help others understand better?

✓ **A culture of positive risk taking:** What are you doing to understand staff experiences, including their fears and worries, in shared decision making scenarios? How do you celebrate the role of team members in enabling people to live full and meaningful lives?

✓ **Inclusion:** How do you collaborate with all team members and people who live in the home to make decisions about the organisation of the home? When do you involve relatives/close friends/partners in decisions about changes within the home? Do people know how these decisions are made?



Involving a person's support circle

Shared decision making often involves, and may need to involve, a wider group of people than the person living in the care home and the team who work there. It can be helpful to think of these other individuals as a person's support circle. These individuals could include family members, a long-standing partner, friend, community advocate and/or attorney through lasting power of attorney, as well as people from wider health and care teams.



Involving these individuals in shared decision making and ensuring they have the opportunity to understand and contribute to decisions can support the quality of life and quality of care for a person living in a care home.

The following practice example shows shared decision making involving a person's support circle in action:

Recognising relationships

Jane moved to live in a care home. She has a daughter who lives 70 miles away who was involved in choosing the right home for her mum.

At least twice a week, Jane is visited by Sylvia, her friend of over 20 years. They spend lots of time together and after Sylvia leaves, Jane becomes sad and unhappy. One member of Jane's care team started to get to know Sylvia and as they chatted it became clearer that the two women were in a loving and supportive partnership, which Jane's daughter was not aware of.

After discussion in team meetings and with the support of Jane's partner, her named worker started to talk to Jane and Sylvia together about involving Sylvia in decisions if Jane did not have capacity at times. The team member also supported Jane and Sylvia to share this agreed involvement with Jane's daughter. With the support of the care home team, Jane, her daughter and Sylvia were able to meet together and agree a plan that was written down and recorded in Jane's care plan.

Positive practice thoughts for involving a person's support circle in shared decision making

- ✓ **Different perspectives:** Have you considered a relative's opinion and/or knowledge of care and do you fully understand how they reached their opinions? Have you collaborated with relatives to come to a compromise, for example by talking through different scenarios and outcomes? E.g. a well-meaning relative may wish for a person's bed to have rails as they believe this will be the safest and therefore best option, without understanding that this may make an individual more distressed.
- ✓ **Your positive risk-taking stance:** Does everyone involved in someone's support circle know about your ethos of supporting shared decision making and 'being, doing and living' when they are thinking about moving into the home, and what this would mean for them? This will help the person to make an informed decision as to whether they are comfortable with this approach and other people involved with them will be aware.
- ✓ **Multidisciplinary meetings:** Have you considered holding these regularly (e.g. monthly) with relatives and other close connections, in order to influence the home direction? This will allow you to learn what they think is working well and what they think could be more frequent.
- ✓ **Supporting individuals in a person's support circle:** Have you asked relatives and other individuals what things might make them feel more supported, engaged and have their voices heard? E.g. through a support forum or a "Friends of our care home" group.
- ✓ **Trusted individuals:** If a relative or other close individual speaks highly of someone who works in the home, have you involved this staff member in decisions? This person has gained the relative's trust and may provide support during decision making.
- ✓ **Being mindful:** Are you staying curious to know whether a relative or other close individual really wants to be involved in decision making and/or is in some cases not acting in the best interest of a person?



SUPPORTING SHARED DECISION MAKING IN CARE HOMES



Shared decision making is an inclusive process where a person works alongside another individual or individuals to reach a decision. People living in care homes have the right to be included in decisions. This includes decisions about their care, as well as everyday 'care-free' decisions.

Shared decision making should also include other people working in and connected to care homes, including team members and other employees, visitors including unpaid carers and other colleagues within health and social care.

Kippers for breakfast

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Positive practice thoughts



- Other perspectives and 'unwise decisions': Have we considered other perspectives, especially regarding a decision we personally would make differently or a decision we might think is 'unwise'?
- A culture of positive risk taking: What are you doing to understand staff experiences, including their fears and worries, in shared decision making scenarios? How do you celebrate the role of team members in enabling people to live full and meaningful lives?
- Trusted individuals: If a relative or other close individual speaks highly of someone who works in the home, have you involved this staff member in decisions? This person has gained the relative's trust and may provide support during decision making.

Want to see more tips, information and practice examples? Read our full guide to shared decision making. **SCAN THE CODE OR VISIT:** myhomelife.org.uk/shared-decision-making-guide



Policy and legislation information

The principle of shared decision making is key to protecting the rights of a person who receives health and social care in England. Many laws and regulations that are relevant to people who provide and receive health and social care can help to navigate the difficult questions around shared decision making, including:

- How to treat people equally, fairly and with a view to protect people's rights and freedoms when making decisions together.
- How to determine whether someone might not be able to make decisions over their own care.
- How to practice shared decision making when someone is deemed not to be in a position to make decisions over their own care.

These are some of the laws and regulations that are particularly important to keep in mind when thinking about shared decision making in care homes:

Human Rights Act

The [Human Rights Act](#) translates the European Convention of Human Rights (ECHR) into UK Law. This means that people in the UK can claim their ECHR rights directly in British courts of law. Shared decision making can help to respect, protect and further the rights of people in care homes, which are set out in the Human Rights Act, for example the right to privacy and family life or the right to social participation. For more information on human rights and how it applies to health and social care, visit the resources of organisations like the British Institute of Human Rights.

Equality Act 2010

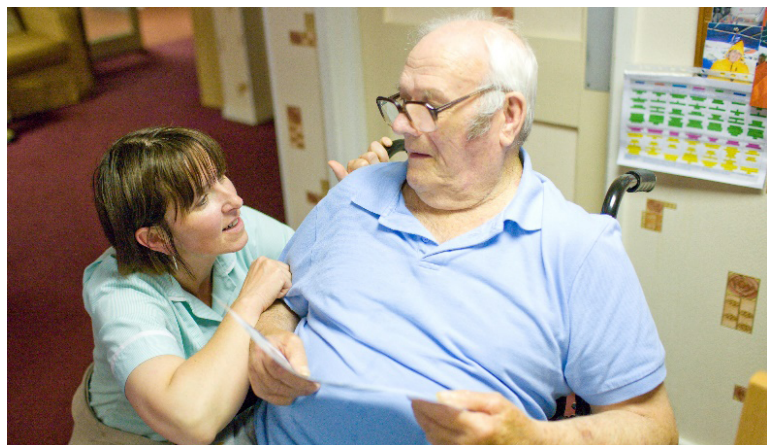
[The Equality Act 2010](#) protects people from discrimination at the workplace and in society based on personal characteristics, such as age, gender and ethnicity. In shared decision making, it is important to treat people fairly and equally regardless of who they are or where they come from. For more information on the Equality Act 2010 and what it means for your life and work, visit the website of the Equality and Human Rights Commission.

Care Act 2014

Empowerment to make decisions over care and support is at the heart of the [Care Act 2014](#). Under the Act, local authorities must make sure that people who live in their area have access to services to prevent reasons for needing care in the future and to provide information and support to make good decisions about their care. Authorities must also make available a range of different high-quality services to choose from.

Mental Health Act 2007

[The Mental Health Act](#) sets out the rights of people detained or receiving treatment in the community for mental illness. Under the Act people have the right to an independent mental health advocate to support shared decision making even if they are deemed not to be able to make decisions regarding their treatment themselves.



Mental Capacity Act

[The Mental Capacity Act](#) sets out under what conditions a person may be deemed not to have capacity to make a certain decision. The Mental Capacity Act also protects people's rights regarding decision making. For example, it determines that people cannot simply be stripped of their capacity to make a decision because this decision may seem 'unwise' to others. The Act also sets out conditions for restraining or restricting a person's liberty if this is deemed to be in their best interest.

Health and Social Care Act

The aim of the [Health and Social Care Act 2012](#) is to empower people receiving health and social care to determine their own care. The Care Quality Commission (CQC), which regulates and inspects health and social care providers in England, was set up because of the Act. The CQC looks for how shared decision making is put into practice in care homes when an inspector visits the home.

NHS Continuing Healthcare Framework

The [NHS Continuing Healthcare](#) framework sets out the principles and processes for determining eligibility for someone to receive a continuing package of health and social care following a primary health need. Again, shared decision making is at the heart of this framework to support high quality, person-led care.

Acknowledgements

This guide on shared decision making was co-created by My Home Life England alongside an Expert Advisory Group of people working in a range of care homes representing the diversity of the sector. The group met virtually over a period of 5 months in early/mid 2021 during the COVID-19 pandemic and their insights and expertise helped to inform and shape the content of this guide.

When reviewing the original 2008 My Home Life bulletin of ‘shared decision making’, we were conscious that, whilst a lot of the content was still really relevant and helpful, many things had changed. In particular we wanted this guide to be led by those working in care homes today.

Thank you to the following for being so generous with your expertise and support:

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