

Whole Family Approach Case Study – Dementia

A Welsh family currently living in rural Essex, Lynnette (81) lives with her daughter, Christine (60). Lynnette has a diagnosis of dementia.



Lynette lives in rural Essex with her daughter, Christine. She moved in with Christine just under two years ago after finding it increasingly difficult to manage in her own home. The family have not historically had regular contact with support services, and engagement with services is new to them. Since her diagnosis of dementia, Lynette's need for daily support has continued to grow, with Christine becoming her primary carer.

Christine's marriage subsequently broke down, with her caring responsibilities for her mother being a significant contributing factor. Although Christine's two daughters live locally, her relationship with them has become strained following the divorce and the considerable amount of time she must dedicate to caring for Lynette.

As her caring role has intensified, Christine has had to reduce her working hours and has had limited opportunity to maintain regular contact with family and friends.

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Lynnette

- Daily routine is very important to Lynnette and having structure each day reassures her. This comes from her years as a matron, where timing and organisation were essential. She has breakfast around 9:30am and ends with a cup of tea, which she insists on making herself due to her strong independence. After losing her husband when Christine was born, she has always managed everything on her own.
- Recently, daily tasks have become harder. Lynnette often forgets where things are or the order of tasks, leaving her overwhelmed. This worries Christine, who fears her mum may one day burn herself with the kettle. Christine stays close by during breakfast and lunch preparation but only steps in when necessary, knowing how important these small tasks are to her mum.

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Lynnette

- In the afternoon after lunch, Lynnette will watch tv and listen to music until dinner time and she will frequently nap. If this routine changes, such as, if Christine needs to go out or unexpected visitors call round, she feels unsettled and can get frustrated. She used to go out for a walk on the weekends into town but now she forgets the way there and ends up getting confused. She misses seeing her friends and getting out in the fresh air to help in the garden.
- Getting up and down the stairs is becoming more difficult for Lynnette which is a concern for Christine, she has raised moving her mum's bed downstairs, but Lynnette dismisses the suggestion. Personal care can be challenging as Lynnette is requiring more support to wash and dress herself which is difficult for them both as Christine knows Lynnette feels uncomfortable and embarrassed. Her forgetfulness and confusion have also started to affect her conversations as she can't remember certain words which is frustrating for her, and she forgets things she has been told which can then cause stress between herself and Christine as there is a lot of repetition.

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Christine

- Christine is becoming increasingly isolated because any change to Lynnette's routine, such as Christine leaving the house, causes Lynnette anxiety and can lead to arguments. Going out together is also difficult, as Lynnette's shifting moods make social situations challenging, so they tend to avoid it.
- Lynnette doesn't sleep well and will be awake for a few hours during the night. This is due to daytime napping, medication side effects, and years of night-shift work. Although she stays in her room and rarely needs assistance, the noise wakes Christine, who then struggles to fall back asleep. This leaves her exhausted during the day.

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Christine

- Caring for her mum contributed to the breakdown of Christine's marriage. She felt forced to choose between continuing to care for her mother or stepping back; she chose to continue, moving Lynnette into the house after her husband left. She still holds some resentment and often thinks back to when she was happier. Her depression has worsened with her ongoing tiredness, and although her daughters encourage her to speak to the GP, she dismisses this because her mum's health always comes first. She has thought about talking therapies in the past but she feels it's difficult to find the time. She also experiences frequent headaches, possibly linked to high blood pressure.
- Stress over the years has strained her relationship with her daughters, who still feel some resentment about the marriage breakdown and the limited time she spends with their children. They visit occasionally, but not often. Christine would love more time with her grandchildren and hopes to return to floristry, which she greatly enjoyed. She misses having a routine and interacting with customers. She also believes that encouraging Lynnette to reconnect with past hobbies, such as choir or gardening, could bring her mother joy.

Reflections



Questions for reflection:

- Do we understand the impact of presenting behaviour on the person and those in the household? What is day to day life like and how much risk and harm may the presenting behaviour cause for others and does this need intervention?
- What are the family beliefs, rules, values and fears that stop them seeking and accessing support? How can we support people to consider their options?
- Have you sufficiently considered the history of the household members and impact of this, adverse childhood experiences, trauma and repeat behaviours and patterns?
- When people are only just doing enough, but change isn't being seen, how is this recognised and how do you respond to it?
- Do we understand the impact of the caring responsibility on the care giver; is this a reasonable impact or do they need support? (what is reasonable?)

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Reflections



When you consider making referrals or signposting

- How do you decide if it is necessary and proportionate?
- Do you consider if the family member needs an introduction to a new service; will they self-refer without support?
- Have you considered their level of confidence and does this mean they need practical support?
- Have you considered family rules, culture, beliefs and values and how this can impact on making the referral or affect future intervention?
- How does your own values and biases influence the interpretation of need?

**Pause here and form your own
conclusions.**

**Please only proceed once you
have done so.**

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Learning points

Preserving identity/dignity and choice

- It is important not to lose people's identities when practicing the whole family approach. Individual voices and views need to be heard and considered to better influence the wellbeing of the whole family.
- Supporting independence is vital for improving the quality of life for people with dementia. As independence is closely linked to identity and self-worth; maintaining it helps preserve dignity and a sense of purpose.
- By continuing to pursue the activities that they enjoy, such as painting or gardening, it can improve emotional wellbeing and give them a sense of satisfaction and fulfilment.
- Exercising choice and having control over everyday can help individuals feel more engaged, alert, and connected to both their past and present. Also, completing a task can provide a strong sense of accomplishment, helping to ease the frustration and confusion that often come with dementia.

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Learning points – continued

Preserving identity/dignity and choice

- Independence also encourages social interaction. When individuals can make choices about their daily routines or engage in conversations, they are more likely to take part in social activities. These interactions are essential for emotional and cognitive stimulation and can help slow cognitive decline. Research shows that even one hour of social interaction per week can reduce agitation and improve quality of life for people living with dementia.
- Promoting independence can ease caregiver strain and helps create a more balanced relationship.

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Learning points

Carers

- The Whole Family Approach recognises that the ‘wellbeing of carers is closely connected to the wellbeing of the entire family’ (Good Practice Guide – A Whole Family Approach to Supporting Carers). When carers are supported and feel equipped to manage their responsibilities, the people they care for, and the wider family are more likely to experience better outcomes.
- Whole-family approaches can also maximise the impact of resources by identifying opportunities to support carers and reduce the very real risks to their health and wellbeing.
- Anticipated changes within the family that may affect the levels of support and care needed and the possible impact of these should be identified early by forward planning and thinking about what the future may look like.

Examples of outcomes



Example outcomes and benefits for carers from a whole family approach	
Short term	- Increased opportunities for families to enjoy time together - Improves accessibility to support - More accurate identification of carer needs
Medium term	- Reduced stress associated with caregiving responsibilities - Improved peer support mechanisms for carers
Longer term	- Better management of unique family dynamics - Improved family cohesion

Credit: Good practice guide:
A whole family approach to
supporting carers

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Options available to Lynette



Lynnette: What does a good life look like for you and your family, and how can we work together to achieve it?

- Explore the option of a few hours a week with a Personal Assistant to walk into town, help with gardening and visit friends
- Care Act assessment
- Explore technology to maintain her independence and help her rediscover her love for singing and gardening
- Discussion with Christine and social care team regarding contingency and planning for the future
- Alzheimer's Society activity groups

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Options available to Christine



Christine: What does a good life look like for you and your family, and how can we work together to achieve it?

- Explore home adaptations and technology to assist with Lynnette maintaining her independence
- Signposting to local carers support groups/ advocacy services and activity groups
- Discussion with Lynnette, her daughters and the social care team regarding contingency and planning for the future
- Signposting to respite and wellbeing services
- Access to talking therapy or psychological input via GP referral/ and health check with GP
- Request a Care Act assessment for Lynnette
- Consider a Mental Capacity Act Assessment for Lynnette
- Request information on Lasting Power of Attorney and Deprivation of Liberty Safeguarding

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Resources and helpful links



Abbeyfield Living Society – [The significance of independence for people living with dementia](#)

Carers Trust – [A Whole Family Approach to supporting carers](#)

[The Care Act and Whole-Family Approaches](#)

Carers Trust – [About caring](#)

Alzheimer's Society – [Activity Groups](#)

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Outcomes



Lynnette

The social worker, assigned to Lynnette, talked to her to understand what she wanted, what her concerns were and what is important to her.

To understand Lynnette's needs more, a care act assessment was carried out and it confirmed that she was care act eligible.

Working in partnership with Lynnette and Christine, it was decided that some assistive technology should be trialled in the house. This included a smart speaker to play music and for Lynnette to sing along to, a kettle tipper to help with making tea and adaptive clothing to make dressing, undressing and using the toilet easier, for example, clothing with Velcro rather than buttons. A shower seat was also installed so that it would be easier for Lynnette to wash herself unassisted.

The Occupational Therapist visited Lynnette and Christine and spoke about possible adaptations to assist day to day living and Lynnette said that she wanted her bedroom to remain upstairs but would like assistance to use the stairs. To help with this a grab rail was installed. A nightlight and easy read clock were also bought to support Lynnette during the night.

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Outcomes



Lynnette continued

A Personal Assistant now spends a few hours during the week with Lynnette, helping her to do some gardening, visit town, go out walking and go to a dementia singing group.

To help rebuild her support network, especially with her granddaughters, Christine invites them round regularly throughout the week at the same time and puts a reminder on Lynnette's smart speaker so she is reminded of their expected arrival. This has started to become part of Lynnette's weekly routine, and she looked forward to seeing them.

With the support of social care, the family have also been able to discuss future planning, put appropriate arrangements in place and consider the need for Lasting Power of Attorney (LPA) and Deprivation of Liberty Safeguards (DoLS). Lynnette has been central to these discussions and is involved in all of them to make sure her voice is heard.

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Outcomes



Christine

Christine is starting to feel more like herself again. The social care team working with her mum took a proactive approach to promote her wellbeing, aiming to prevent deterioration in her depression and blood pressure and to reduce the risk of a crisis. She was directed towards talking therapies and Cognitive Behaviour Therapy which helped a lot and had appointments with the GP and nurse to talk about her blood pressure.

With Lynnette going out more during the week, Christine has been able to spend more time doing things that she enjoys such as seeing her grandchildren. She has also accessed support through the Dementia UK forum and local carer networks, where she has learned practical strategies to make daily life easier, such as leaving written reminders and using a whiteboard for notes.

As her mum is now active through the week, she is sleeping better through the night which has in turn helped Christine's sleeping and positively affected her general wellbeing; physical and mentally.

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Outcomes



Christine continued

The introduction of assistive technology to support her mother in maintaining and regaining elements of her independence has significantly reduced Christine's stress. The use of a smart speaker allows her to set reminders for her mother, including updates about her whereabouts and expected return time when she needs to leave the house. This has enabled Christine to step out for short periods with greater reassurance. In addition, the installation of Telecare systems has increased her confidence, as she will be alerted immediately should anything unusual occur.

Regular visits from her daughters have also helped Lynnette become increasingly comfortable with them, and vice versa. This has enabled them to provide respite for Christine and have helped them rebuild their relationship with both their mum and grandmother.