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Supporting Carers of People Living with Dementia at End of Life Summary Report

IMPACT Facilitator Project 2022/23 (Wales)

Leanne Taylor, July 2023

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Background

The Hospice of the Valleys is based in a small Welsh town, Ebbw Vale, serving the Blaenau Gwent region. Its workforce provides comprehensive support to people diagnosed with life-limiting conditions and their families and carers. The small, but highly skilled, multidisciplinary team is made up of nurses, doctors, social care workers, health care support assistants, benefits advisors, holistic therapists, operational and volunteers who are able to offer a wide range of clinical, emotional, and practical support to people living with life limiting conditions residing in the area. Sitting within the hospice is Cariad, a specialist dementia service providing support to individuals and families living with the arising difficulties that come with a dementia diagnosis. The facilitator was located within this part of the hospice provision.

The Facilitator role

IMPACT Facilitators support bottom-up change. They are hosted within a local organisation for a period of one year to deliver an evidence-informed change project, responding to local issues. Drawing on evidence from research, lived experience and practice knowledge, Facilitators co-design a local project, review evidence of what works, and work with diverse stakeholders to implement the project in practice. Findings and outcomes are then shared with others for learning and replication across the sector. In July 2022, the IMPACT Facilitator role was introduced to the Hospice of the Valleys (hospice) to support the implementation of evidence with carers of people living with dementia.

The evidence base

IMPACT engaged with evidence from University College London (UCL) research project, ‘Supporting family carers of people with dementia at the end of life: Developing a decision aid’ (hereafter referred to as SALSA). Although referred to as a decision aid, this is a booklet to support conversations with families about what matter to them that may be overlooked by more traditional services or support. SALSA worked with people with dementia, carer and professionals to better understand the issues that might arise at the end of life and developed a decision aid

(see Davies et al., 2021). SALSA noted the following points in relation to decision making at the end of life:

- While it is always important to ensure the person living with dementia is empowered to make their own decisions, this becomes increasingly harder to achieve as the illness progresses.
- The process currently used in the UK to support people living with dementia and their families to plan for the future, called Advanced Care Planning, has gaps that do not fully address the complexities that arise when someone living with dementia begins to lose their ability to make decisions.
- Decision aids have been developed in the past, but they have been limited in scope, tended to focus on one topic or area of care, and did not consider the full spectrum of complex decisions faced by people living with dementia at end of life and their carers.

SALSA piloted their decision aid tool at a series of workshops where key stakeholders were invited to provide their feedback and thoughts on the tool’s effectiveness with carers of people living with dementia. These included:

- People living with mild cognitive impairment or dementia.
- Unpaid carers of people living with dementia; this mostly included family carers.
- Health and social care practitioners that supported people living with dementia toward the end of their lives.

Key findings and feedback which shaped final content of the Decision Aid

- All workshop participants thought it important to identify and highlight the person responsible for making decisions, and not to assume that family carers were always the designated decision makers.
- All participants felt that carers would find the tool easier to relate to if stories and case studies were included in addition to standard information and facts.
- Participant feedback resulted in the decision aid being designed to be a dynamic and iterative tool that could be revisited and reflected on by decision makers during the dementia and caring journey.

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- Key decision areas were explored and agreed on by designers with the support of the participants. These included:

Changes in care arrangements. This related to moving into a care home, hospital admissions, and changes in the level of homecare. All stakeholders agreed that this was one of the most common and important decisions. The need to provide information to carers who were both state funded and private funded was highlighted.

Eating and drinking. Findings revealed that family carers felt under informed about this area.

Everyday well-being of person with dementia. This encompassed physical as well as mental and emotional wellbeing. Continence was seen as a specific challenge that needed to be addressed within this area.

Healthcare, tests, medication. The workshops with professionals and people living with dementia highlighted that many of these decisions should not be solely carers’ responsibility but should be shared with the healthcare team.

At the time of writing the decision aid tool is not publicly available but it was shared with IMPACT to inform this Facilitator project.

Local theory of change

IMPACT and Hospice of the Valleys (hereafter referred to as the hospice) agreed that the Facilitator role would introduce the decision aid and its supporting evidence base within the hospice, to support work with carers of people living with dementia at end of life. Subsequently, a local theory of change was developed collaboratively between IMPACT and the hospice to demonstrate how far the Facilitator could use this evidence to support local change, as summarised below.

The local need and context

The hospice’s dementia service, Cariad, is a small service that had limited information on the carers of people with dementia they supported, and their specific

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needs. It was important that this knowledge gap was addressed because while the hospice was providing valuable support to individuals with dementia and their carers, there was not a detailed enough understanding of carers’ key challenges, nor the impact of the hospice’s work with them. As part of this, the hospice acknowledged that while there was a substantial amount of activity and support dedicated to people living with cancer and other life limiting illnesses and their carers, more dialogue and work was needed to recognise the experiences and needs of people living with dementia and their carers.

What were we trying to change?

In addition to improving the documentation and understanding of the hospice’s work with carers, the hospice identified a need for the IMPACT Facilitator role to:

- **Understand the efficacy of the decision aid tool in supporting carers to access timely information and support.** It was hoped that the decision aid would add to the support that the hospice provided to carers. Alternatively, it would be important to understand factors that may have affected its usability should that be the case.
- **Identify gaps from carers and staff in their support or knowledge related to carer decision making.** The hospice hoped to improve its understanding of the support needs of carers of people living with dementia, and to identify related staff development needs.
- **Proactively shape the hospice provision for carers of people with dementia at end of life.** It was hoped that the Facilitator’s presence would lead to expanded relevant support for carers of people living with dementia.

Main activities

To achieve the above aims, the following work was undertaken:

- Developing tools to help the staff reflect on their experience of using the decision aid;
- Supporting staff to reflect on carers’ response to the decision aid;

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- Working alongside Cariad during their patient reviews and team meetings to identify carers and families to introduce the tool to. This work took place during the first months of the Facilitator role. In total, Cariad staff introduced and attempted to engage seven family carers with the decision aid.
- Building a strong relationship with the hospice staff by holding planned and ad hoc meetings with senior staff; initiating and supporting topic based working groups; and having informal, unplanned conversations with staff. Approximately 12 of the hospice’s staff have been introduced to the decision aid tool and engaged in in-depth conversations on its potential role in the hospice. This included the Cariad service, the hospice’s family support team, its benefits service, and nurses.
- Building a dialogue with carers by holding one to one meetings and a focus group. 11 carers were engaged in these Facilitator-led conversations.
- Carrying out desk-based research which allowed an exploration of local and national priorities and projects, existing evidence bases, including other carer support tools.
- Collating and presenting evidence to the hospice so that meaningful follow-up work could be planned to support its work with carers.

Planned benefits

The hospice and IMPACT envisioned that this work would initially result in carers feeling more informed, valued and supported, as well as the hospice having a greater grasp of the dementia care landscape in terms of the support available to carers of people living with dementia. The hospice had longer term aims to build on the knowledge and lessons learnt from Facilitator project developed to influence how carers of people with dementia are worked with at regional and national levels.

What have we learnt?

A considerable amount of learning was gained from implementing the Decision Aid tool and its surrounding evidence in the hospice. These lessons materialised as

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factors that 1) challenged or hindered the implementation of evidence, and, 2) supported, or provided opportunities for the implementation of evidence.

Challenges

Care service priorities: The Facilitator observed how implementing evidence in social care settings can interact with existing service priorities and workloads. In the hospice, staff time was stretched and they needed to prioritise the everyday and emerging critical needs of patients and carers. The Facilitator model presented a new dimension to the hospice’s work, including, engaging with the evidence base, additional reflection time, and exploring new ways of working. Difficulties were presented in staff needing to weigh up attending to patients’ and carers’ everyday pertinent needs against a need to find the time to engage with the decision aid tool. Ultimately, as the hospice is a small service that prioritises the needs of its patient and carer, it proved hard for the staff group as a whole to engage fully with the tool and test it out.

Implementing evidence: There were some important lessons on how evidence may interplay with the identity and values of the care service in which it was being introduced. In this case, the learning related to who the original evidence base was aimed at, and how this interacted with the hospice’s user groups and underpinning ethos. The Cariad service was developed to empower the person living with dementia. This resulted in the service routinely supporting people with dementia to express their wishes. It meant that staff supported families to develop contingency plans where the person with dementia could be listened to even when their decision-making capacity had reduced. In comparison, the decision aid was designed to support carers with appropriate authority to make decisions on behalf of the person living with dementia because they no longer had decision making capacity. This led to some disparity between the aims of the evidence base and the values of the hospice. This difference raised ethical issues as well as logistical ones when introducing the decision aid within this hospice context.

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Legal and policy context: Introducing the decision aid tool in Welsh dementia and hospice care gave rise to important learning in the sector, and, the resultant place of the tool within it. Advanced Care Planning is an approved process to support the decision-making process that people with dementia and their carers undergo in England and Wales. Also, Lasting Power of Attorney under the Mental Capacity Act 2005 assigns legal authority to a person, usually a family member, to make decisions on someone’s behalf once they can no longer do so themselves. Even where Lasting Power of Attorney was in place, staff were concerned that the decision aid may guide carers to determine care arrangements that may be ultimately overridden by the professional providing the care or by best interest decision making panels. This highlights the importance of carefully considering the legal, policy and power context in which an evidence base is being introduced, and also demonstrates how the expertise of local frontline staff can support this insight.

Carer pressures: In many instances, the carers that the Facilitator approached to discuss the decision aid with were navigating their caring role alongside work priorities and their own changing personal circumstances. As a result, some carers booked in meetings that they were unable to attend on several occasions. Carriad staff experienced the same issue when attempting to introduce the decision aid to carers and were often confronted by needs that were more urgent than engaging with a new practice tool. This made it challenging to gain extensive insight on the tool and its effectiveness from a carer perspective. Importantly, it highlighted the ongoing pressures carers face, and reiterated the need to work sensitively to avoid adding to this pressure when introducing change to social care settings.

Opportunities

Hospice’s strategic role: IMPACT gained valuable learning on the potential strategic role of local services when implementing evidence. The hospice’s leaders and strategic team were helpful in highlighting the aims the hospice shared with the IMPACT local theory of change. They were able to effectively convey and integrate these aims into the hospice’s routine work by including discussion about the decision aid in hospice-wide meetings, running topic based working groups, and undertaking

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planning work with the Facilitator. In these ways, the focus and dedication of the hospice’s strategic team enabled the Facilitator to effectively share the evidence base locally, and illustrated the value of gaining the strategic support of local services.

Reviewing the local theory of change: The hospice and IMPACT collaboratively revisited the original theory of change. The process allowed a re-formulation of the project aims to broaden the focus to supporting carers more generally. Whilst staff were unsure that this specific tool would work for them, due to the (earlier) stage of dementia in their family member who in most cases retained capacity, it acted as a catalyst to seek other tools that may be more appropriate. The importance of structuring conversations remained relevant along with ensuring that this also included areas that were important to families but may be overlooked by formal services.

Where relevant, the hospice and Facilitator were able to identify an alternative, but relevant, evidence base and tools that may support the meeting of these aims. This process revealed the value of reflexively and flexibly working with evidence to support change.

End of life conversations: Introducing the original evidence base (the decision aid) to the hospice’s partner organisations, led to key lessons on dementia care sector priorities. Conversations on end of life is an emerging care sector priority that is becoming increasingly recognised as an area too often designated to specialist organisations which places great pressure on already strained services. The decision aid tool was seen as playing a potentially valuable role in encouraging conversations on this matter. This learning allowed IMPACT to consider the ways in which the tool could be scaled in the long term.

In a similar direction, some carers appreciated the tool’s focus on end of life planning. For these carers, it helped them to anticipate the ways in which their family member’s illness may progress and helped them feel “informed”. For this reason, some carers and staff felt the decision aid might be well situated in diagnosis processes and in other dementia services at an earlier stage of the illness’s

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progression. which is another important message to support the scaling of this evidence base.

What difference have we made?

The Facilitator project has delivered some positive outcomes for the work of the hospice that can be built upon, in the longer term, to improve the support that carers receive. These include:

- increase in hospice discussions and work related to supporting carers
- greater opportunities for carers of people living with dementia to inform the hospice’s work
- enhanced the hospice’s understanding of carers and the support they might need
- hospice’s explicit engagement with key national policy developments evidence bases and dialogues, including the All Wales Dementia Care Pathway of Standards (Improvement Cymru, 2021)
- consolidation of hospice’s relationship with key dementia and carer organisations in Wales.

Evidence of these outcomes

The hospice established some interventions during the Facilitator project that will hopefully provide a strong basis to take their work with carers forward:

- **Reinstating Carer Support Needs Assessment Tool (CSNAT) and associated recording processes:** The hospice drew on the Facilitator’s role to improve how it captured and documented its work with carers and their needs. This led to a re-engagement with evidence that stimulated discussion on carer needs assessments. This led to the reinstatement of the carer needs assessment process within the hospice, as well as the recording tools and planning needed to support this work.
- **Carer’s recording database:** The Facilitator worked with the hospice’s administration team to begin refining its recording tools and databases. All carer need will be recorded in these systems, alongside the interventions and referral support provided to them by the hospice. As well as enabling all work

done with carers to be systematically recorded and tracked, these databases will also contribute to an improvement in the hospice’s recording practice and culture. Importantly, this data will support the hospice’s aim of being in a position to use evidence gathered to apply for further support to sustain and advance their carers’ support package.

- **Partnerships to support carers:** The capacity of the hospice to support carers has been initially enhanced by developing helpful partnerships. These partnerships have also begun to underscore the hospice’s role in the Welsh dementia care landscape. One of these partnerships is with Improvement Cymru who has offered to support the hospice’s recording of carer need and experience. Improvement Cymru has also offered to inform the hospice’s approach to holding meaningful conversations with carers to support a rich understanding of carer need. In addition, the hospice has recently started discussion with Swansea University’s Developing Evidenced Enriched Practice (DEEP) project which seek to improve the use of evidence in health and social care practice. Specifically, they are interested in exploring the use of a story gathering research method to better understand how their provision improves carers’ wellbeing and quality of life.
- **Carer insight summary:** The Facilitator model has enabled carers to directly voice their needs in relation to their caring role, identity, difficulties, and the decision aid tool. They have been able to highlight their key challenges, including the dementia diagnosis process; their support networks; maintaining their relationship with the person living with dementia; employment and income issues; maintaining their identity, and supporting their well-being. In many cases, these challenges have resulted in exhaustion, loneliness, and mental health difficulties for carers. These issues have been summarised in a carers’ insight document which the hospice have already begun to draw upon to evidence carer needs to funders, initiate further discussion with carers and plan future support.
- **Planning to support the hospice’s proactive engagement with national standards:** The hospice leads and the Facilitator drafted an internal action

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plan to map out the hospice how they meet and evidence the Welsh Dementia Standards and contribute to national dementia care planning.

Concluding comments

IMPACT’s work with the Hospice of the Valleys led to some valuable lessons and outcomes. From a Facilitator perspective, key to this was the safe and trusting rapport developed between the IMPACT Facilitator and the hospice staff, which enabled honest, educational, and productive dialogues and work to take place. The work undertaken will be of interest to the wider hospice movement, and other organisations who are keen to improve the end-of-life experience for people living with dementia and their carers. More widely, this project has demonstrated there is a two-way relationship between evidence and practice. Tools developed elsewhere are not necessarily a blueprint for implementation, but they can form the basis for local discussion, exploration and negotiation about what might work. This learning from practice can then inform future research to improve the current evidence base. IMPACT looks forward to following the hospice’s journey.

Reference list

Andrews, N. (no date). ‘Developing Evidence Enriched Practice (DEEP)’. *Swansea University*. Available at: <https://www.swansea.ac.uk/research/research-highlights/health-innovation/developing-evidence-enriched-practice/> (Accessed 22.05.2023)

CSNAT-I. (2022). *The Carer Support Needs Assessment Tool Intervention (CSNAT-I)*. Available at: <https://csnat.org/> (Accessed: 12.12.2022)

Davies, N. *et al.* (2021). ‘A decision aid to support family carers of people living with dementia towards the end-of-life: Coproduction process, outcome and reflections’, *Health expectations : an international journal of public participation in health care and health policy*, 24(5), pp. 1677–1691. doi:10.1111/hex.13307.

Hospice of the Valleys. (2022). *Three-year strategy 2022-25*. Hospice of the Valleys. Available at: https://www.hospiceofthevalleys.org.uk/wp-content/uploads/2023/01/HoV_A4_StrategyDoc_FINAL_spreadslow.pdf (Accessed on 10.02.2023)

Improvement Cymru. (2021). *All Wales Dementia Care Pathway of Standards*. Available at: abuhb.nhs.wales/files/dementia/dementia-standards-pathway-document-english-finalpdf/. (Accessed. 05.08.2022)