

Summary Report

Creating an Alternative Support Pathway for Older Informal Carers

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Research Summary

The UK population is rapidly ageing, with one in seven people projected to be over 75 years old by 2040. While it is positive that we are living longer than ever, this does mean that more people are ageing with multiple long-term conditions (MLTC or multimorbidity). MLTC can have a negative impact on all aspects of a person's life, including their quality of life and mental health and their ability to function independently. People with MLTC often depend on additional informal or unpaid support from family and friends to maintain their independence and quality of life.

Providing such care can negatively affect carers' health and wellbeing, especially the growing number of older carers who live with long-term conditions themselves. Considering the increasing dependency on informal care to support an ageing population, providing accessible and tailored support services to older informal carers is critical.

Adult day-care centres offer vital support for people living with MLTC and disabilities while also providing essential respite for their carers. These centres are well placed to offer carers the necessary resources, skills, and support to enhance their wellbeing — addressing the urgent and often overlooked challenges of caregiving.

In partnering with a day-care centre and a community organisation supporting South Asian communities living with MLTC, we hosted four co-design workshops to identify unmet support needs and priorities of older informal carers. We explored potential support pathways and produced an intervention with supporting resources. Through this collaborative process, we created an alternative support pathway prototype, which includes the following components:

Resources: Personalised materials and resources, which make part of a 'Carer Box' (Figure 1), focused on signposting carers to local support services and providing practical tools to improve self-care and overall health and wellbeing.

Services: A combination of group-based educational and psychosocial services concepts, with accompanying manuals and informational materials.



Image 1: Carer Box

What is the problem?

Health and social care in the UK face several challenges: increasing demand for healthcare services with insufficient funding, staff shortages, and an existing backlog of patients.¹ These have led to a growing burden on family and friends to support an ageing population with a higher prevalence of MLTC and complex healthcare needs.²

Caring for others is a challenging and varied experience, as support may include helping with basic activities of daily living (e.g., shopping, cooking, dressing, mobility), attending medical appointments, managing and administering medications, or managing finances and legal affairs. For many family members, friends, or even neighbours, caregiving often stems from a sense of respect and duty and may offer a carer work that is fulfilling; however, it usually comes with a significant burden and toll to carers.³

Recent evidence suggests that caregiving is associated with poor mental and physical health in all age groups and that experiences of caregiving difficulties and

ongoing distress lead to burnout.⁴ Many informal carers are older and managing MLTC themselves, making them especially vulnerable to the impacts of caregiving⁵.

Considering our increasing dependency on carers, providing tailored support services to older informal carers is critical to improving outcomes for carers and those they support. As traditional pathways for accessing resources and support through community link workers and local authorities have become overwhelmed and under-resourced, alternative sources of accessing support within the community are needed.

Alternative pathways currently involve receiving care from health practitioners other than GPs.⁶ However, there is growing interest in pathways that can bring together various organisations (Public Healthcare, Private and 3rd Sector), professionals (pharmacists, psychologists, social workers, etc.), activities (walking groups, community groups, advice, volunteering), and informational resources (telephone helplines or websites).

¹ Fenton K, Fell G, Roberts W, Rae M. The UK Government's mandate for change must prioritise transformation of the public's health. *The Lancet*. 2024;404(10449):223-226.

² Chief Medical Officer's Annual Report 2023 – Health in an Ageing Society.

³ Carers Trust. Experiences of Older Adult Unpaid Carers in Scotland. 2023. Available at: <https://carers.org/policy-and-strategic-influencing-in-scotland/older-adult-unpaid-carers-in-scotland>

⁴ Gérain, P., & Zech, E. Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Frontiers in psychology*. 2019;10, 466359.

⁵ Price ML, Surr CA, Gough B, Ashley L. Experiences and support needs of informal caregivers of people with multimorbidity: a scoping literature review. *Psychology & Health*. 2020;35(1):36-69.

⁶ Scottish Government's Health, Social Care and Sport Committee. Alternative Pathways to Primary Care. 2022. Available at: <https://bprcdn.parliament.scot/published/HSCS/2022/6/17/0e05bfbf-b984-4031-97ee-6129de863e93/HSS062022R09.pdf>

What did we do?

In collaboration with community organisations, such as The Open Door and Networking Key Services, we conducted four co-design workshops with informal carers in Edinburgh. By directly involving carers, we ensured that their needs, experiences, and expectations were placed at the centre of our discussions, making them active participants in co-designing alternative support strategies.

The workshops explored current and potential support pathways available to carers and where these existing services fell short. Through these sessions (Figure

1), we gained insights into carers' unmet needs and ongoing challenges. To guide the discussions, we used a variety of workshop tools. These materials provided visual and conceptual frameworks: helping carers articulate their needs, offering examples of existing support services for adaption, prototyping resources, and service guidance. These tools enabled the co-design of practical and relevant solutions to carers' day-to-day struggles.

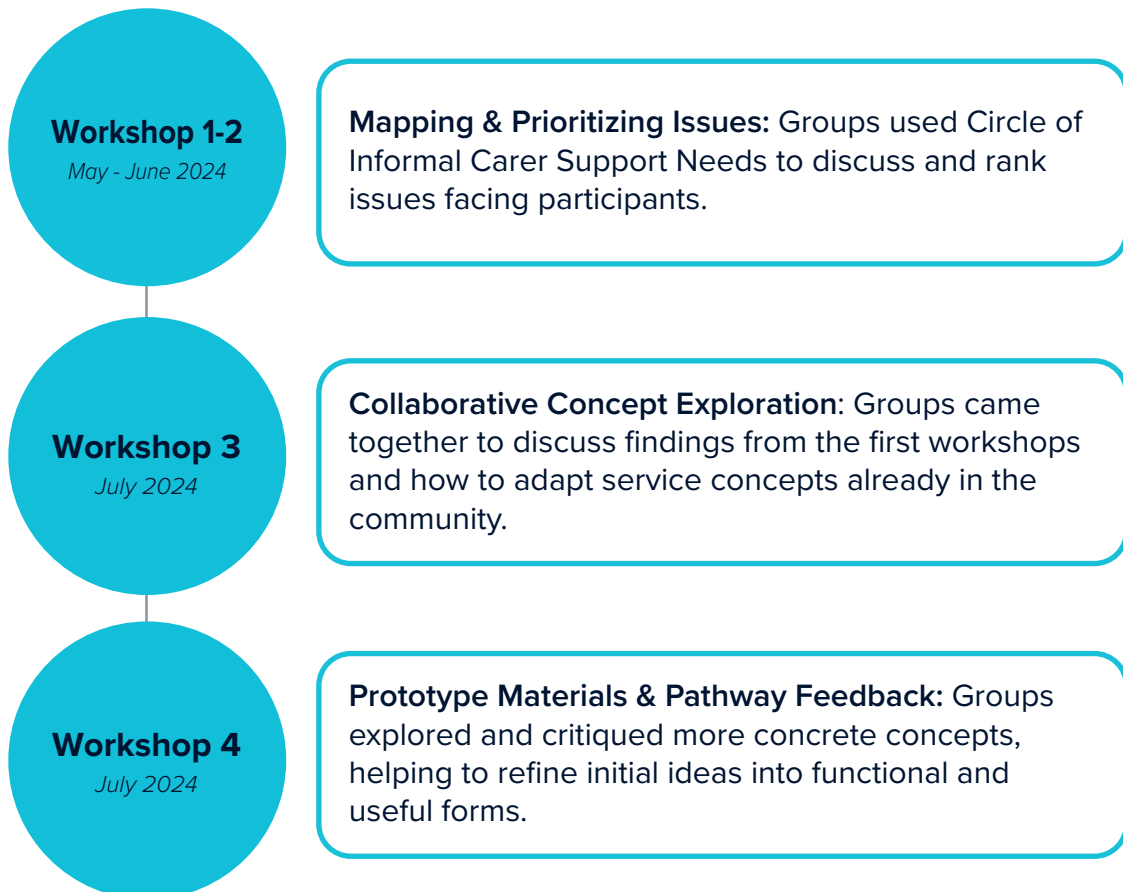


Figure 1: Workshop Series Schedule

Mapping & Prioritizing Issues

Five informal carers participated in the first workshop, and six carers from South Asian backgrounds participated in the second workshop, bringing a diverse range of caregiving experiences and responsibilities. The nature of their care varied; e.g., some were engaged in direct intensive care, while others offered remote or intermittent support. Additionally, the carers were responsible for different family members, including parents, children, and spouses. All participants were living with MLTC, with distinct needs and challenges. This variation in carer roles and the needs of those receiving care underscored the complexity of the informal caregiving landscape.

We began workshops by inviting participants to share their personal caregiving experiences, with a particular focus on the support services they currently access. We used the ‘Circle of Informal Carer Support Needs’ framework (Figure 2) developed in our previous patient and public involvement work with older carers to facilitate these discussions and encourage deeper engagement. The framework served as a valuable prompt, guiding participants to consider different dimensions of caregiving and support needs, such as self-care, emotional support, respite care, and access to information and resources.

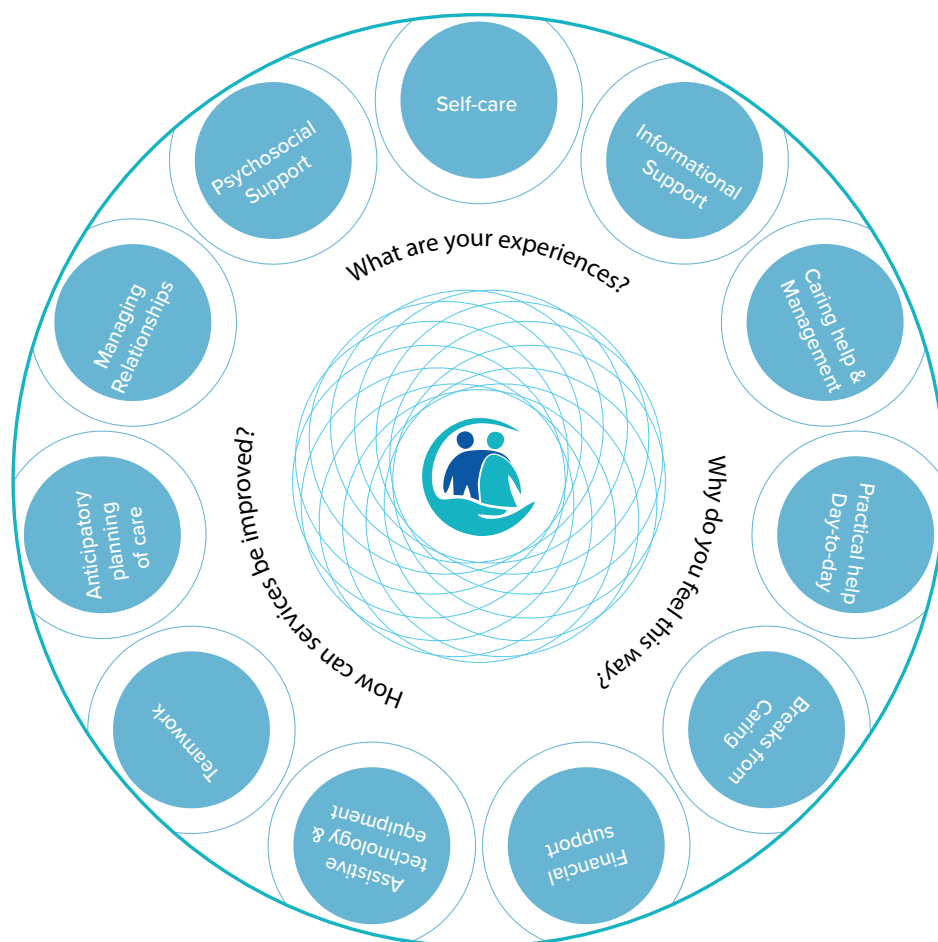


Figure 2: Circle of Informal Carer Support Needs

During these workshops, carers openly expressed their difficulties in accessing support services for themselves and the individuals they care for (Image 2). A recurring theme in their feedback was the challenge of navigating complex systems to find relevant information about local support services: ***“I think there is so much information available, but not one central point.”*** Carers suggested that locating support services they might benefit from was often time-consuming and confusing, adding to emotional and physical strain.

Carers expressed a desire to access MLTC-tailored knowledge and formal care training (e.g., moving, lifting and handling, medication management) but continuously referred to not knowing where to start: ***“I think not knowing what support is available to us is an issue.”***

Participants also stressed the importance of having localised services that are easily accessible within their communities. They emphasised that proximity to services is crucial - ***“What I’m actually looking for is support for myself nearer home”*** - as it reduces logistical barriers and enhances their ability to manage their caregiving responsibilities more effectively. However, services remained overwhelmed and struggled to support them: ***“VOCAL [carers support organisation] is far and has a long waiting list.”***

Those from South Asian communities shared their personal experiences of caring for loved ones, shedding light on the additional challenges they face due to

language and cultural barriers. These carers often found themselves navigating complex healthcare and social service systems where language difficulties made accessing the necessary resources, information, and support harder. They expressed a need for support systems that accommodate language barriers and understand and respect the cultural contexts in which they provide care: ***“I want to go to a support group in our community where those who have issues will be similar to mine.”***

They also indicated that culturally relevant resources and bilingual support staff could significantly impact their ability to navigate caregiving challenges more effectively: ***“What you need is someone who understands your situation, what the alternatives are, and can help you make those decisions.”***

Many carers stressed the intensity of their caregiving duties, which often involved providing 24/7 care without formal support or respite. Cultural norms and expectations further compounded workloads, sometimes discouraging them from seeking external help or identifying themselves as ‘carers.’ Several participants expressed that within their communities, caregiving is often viewed as a natural part of family life, a responsibility that comes with love and duty towards relatives: ***“They fall ill frequently, but they do not realise they are doing everything for people they look after, but we all know, they are full-time carers for their husbands.”***

A key theme from both workshops was the emotionally demanding nature of caregiving. Participants found caring to be mentally ‘draining’, sometimes leading to depression, and requiring: **“support (which) is psychological and emotional.”** Access to mental health support was not always available, but those currently receiving support expressed the positive benefits it had.

As a result, many needed to recognise that they were fulfilling the role of a carer or entitled to support services. They also felt there needed to be a greater understanding by those in charge of services and resources available that general guidance on caregiving is essential:

“If I know how to care better, I’ll adopt that strategy.” It was evident that a holistic approach to care would be needed to understand and address their multifaceted needs and social circumstances.

The insights gained from these workshops provided valuable context for understanding the diverse needs of informal carers and highlighted key areas where support services could be improved or expanded. These initial sessions laid the groundwork for deeper exploration in subsequent workshops, allowing us to identify alternative pathways for more tailored and accessible caregiving support.



Image 2: Workshop Session 1 at Open Door

Collaborative Concept Exploration

The third workshop brought together the eleven participants who participated in the first two workshops to explore priority areas. We presented participants with an ideation map (Figure 3) highlighting key quotes and findings from the previous two workshops. We divided the map into three critical aspects of the support pathway: places, services and resources. We used this tool to guide conversation and encourage participants to share their opinions on how support pathways could be adapted and improved.

Supplementing the map was a collection of reference cards for existing resources, services and place-based supports for participants to explore and discuss throughout the session (Figure 4A & 4B). Those discussed included pathways focused on younger people with mental health needs (Shared Lives), parents with a newborn (Baby Box), or those managing the estate of someone who had passed (Tell Us Once). Cafes to discuss death, pharmacies to facilitate social prescribing, and online directories such as such as EVOC RedBook, to locate support services

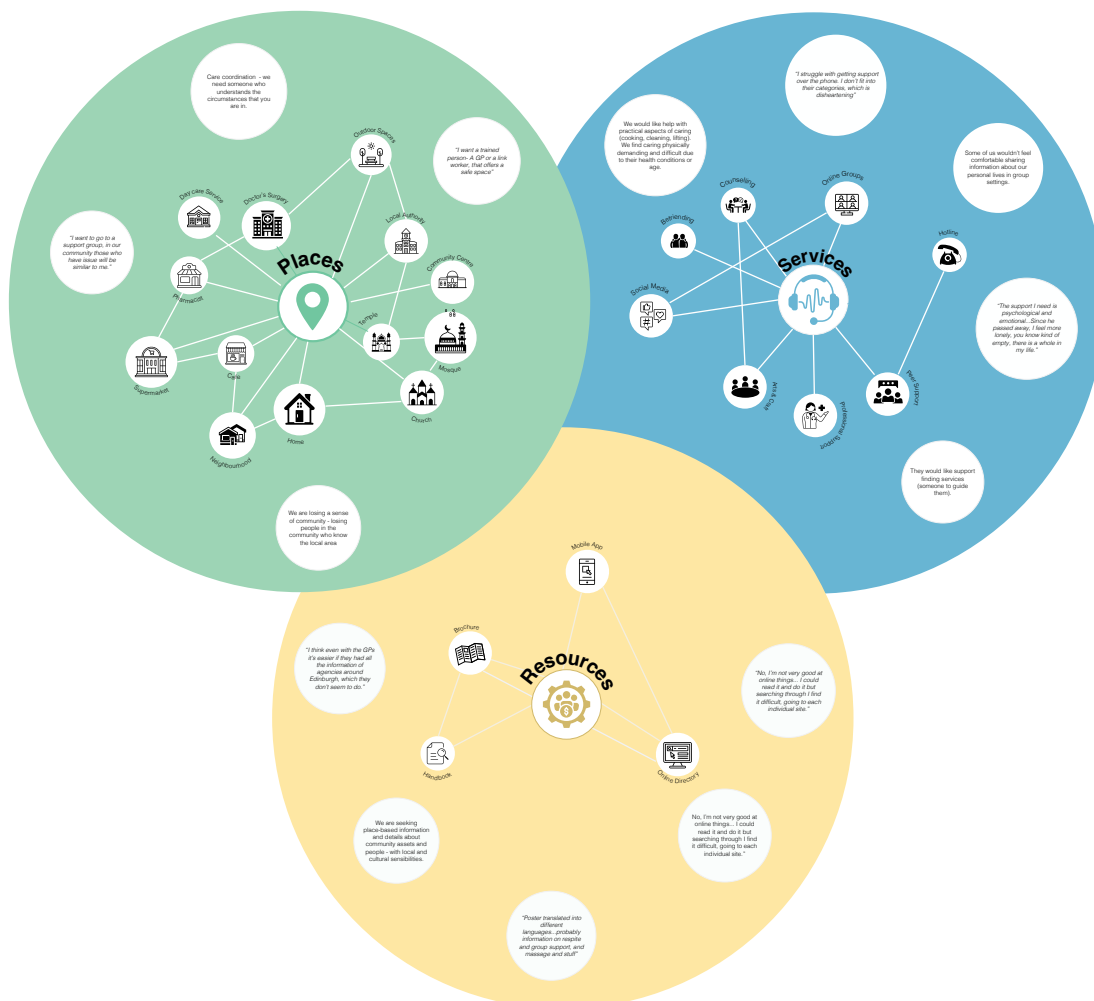


Figure 3: Pathway Ideation Map

Places: Where would you like to receive support?

Examples provided were daycare services, pharmacies, doctor’s surgery, cafes, and religious buildings. Participants had mixed views regarding whether to go to cafes to discuss a sensitive topic, citing privacy. Participants from a South Asian background questioned whether these cafes would be able to provide culturally informed support, such as for grief or bereavement. Instead, they saw mosques and temples as spaces to access resources and support. Participants shared positive views on pharmacies in their communities. However, they did perceive pharmacists as too overwhelmed by their roles to provide personalised care support.

Services: What services would you want to be available?

Examples included counselling, befriending, peer support and arts & crafts. Many participants were unaware of the ‘Tell Us Once’ to report a death or ‘Shared Lives’ care matching service. They were positive about these services and felt they could be adapted to meet their care needs. One of the potential adaptations to Tell Us Once was having the option to make one call that notified authorities had become a carer and linked them with local support services. Participants thought ‘Shared Lives’ was a good idea as it may offer them peace of mind if they knew their loved one had someone checking up on them. However, they expressed wanting options on who the friend may be, for instance, choosing a female friend or of similar background.

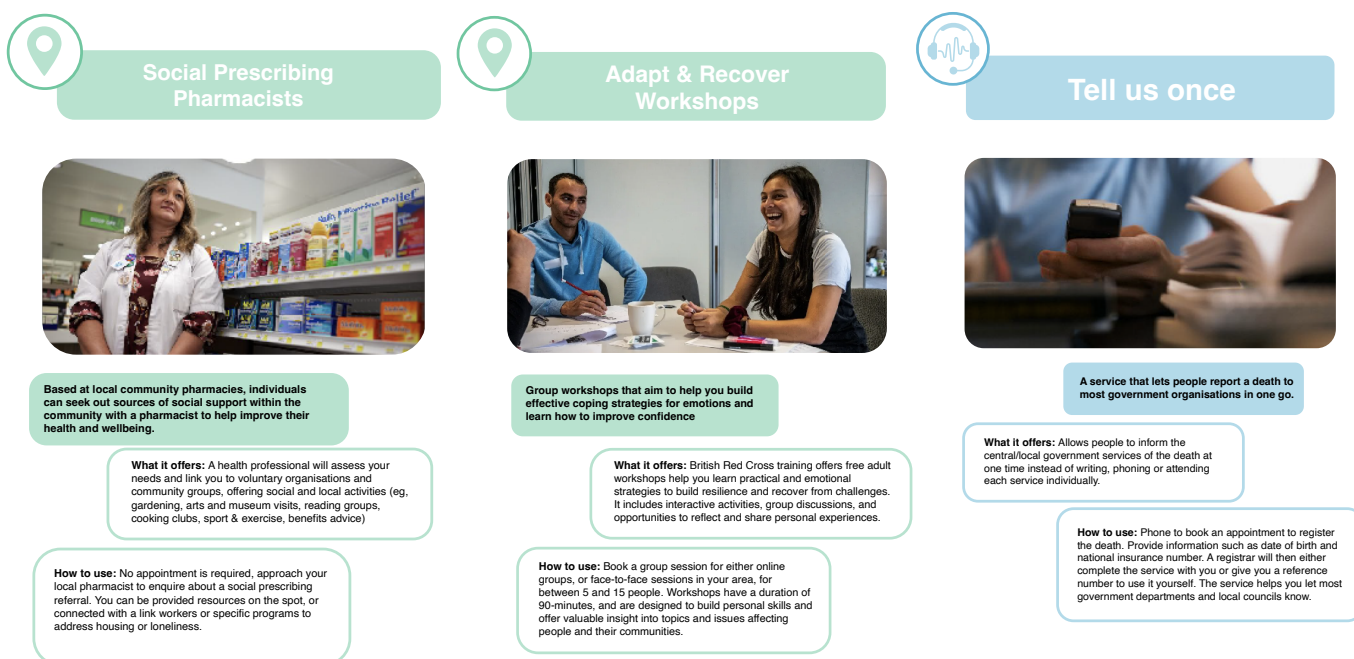


Figure 4A: Workshop 3 Reference Cards

Resources: How could existing resources be adapted to meet your needs?

We provided resource examples to the groups such as the Scottish Baby Box and Mobile Applications. This Baby Box is a physical container full of the essentials for the early months of a baby’s life provided to parents. Adapting the Baby Box for carers was positively received by participants. It was perceived as a helpful way to begin a carer journey that should include informational resources or support tools for carers and the person they care for. Due to a desire for local resources and information, we identified that personalising the boxes with information on local services would significantly benefit carers.

Participants were neutral regarding carer support mobile apps such as e.g., Q&Care Mobile App proposed as a useful concept in our previous patient and public involvement work with older carers. Many felt that apps

could be helpful in personalising support but preferred a trusted source like the National Health Service (NHS) to deliver it. Participants agreed that the Red Book (an online community and voluntary sector organisation directory) was a good idea but had never heard of it. They felt that it needed to be promoted and kept up to date so people could trust and utilise it.

Overall, the participants in our workshop observed a disconnect between available services and awareness of these resources and services. They indicated that central hubs of information, such as local authorities and community organisations, needed to provide the necessary support or information about services they could access. This feedback indicated a clear need for more cohesive communication between services and key individuals who could guide them to services that met their personal needs.



Figure 4B: Workshop 3 Reference Cards

Alternative Pathway Prototype

Caregiving is a dynamic process of role transitions across a continuum, which our participants highlighted through their journeys. In developing our pathway, we saw how important it was to base it on this journey. This carer journey, which too many describe as a career, has been summarised by other researchers across five key phases⁷. Building on this work, we propose 6 phases involving:

Phase 1 (Role Onset): The carer will begin to assist a care recipient in new ways.

Phase 2 (Self-identification): The carer acknowledges their care activities are outside regular familial support.

Phase 3 (Intensifying Workload): The carer feels the needs of a care recipient increase in quantity and intensity to a level that requires additional assistance.

Phase 4 (Seeking Alternatives): The carer explores alternative living arrangements to reduce their increasing caregiving burden.

Phase 5 (Role Reduction): The care recipient moves to a setting to relieve the carer of primary responsibility for care. Most often, this entails placement in an assisted living facility or formalised home support.

Phase 6 (Bereavement): After a short or long period of formalised care, where the carer likely remains engaged, the recipient may pass away, leading to additional needs for the carer post-caregiving.

In the context of MLTC, caregiving roles evolve from existing relationships and undergo continuous change as the complexity of health conditions and the needs of people living with MLTC increase. This change process involves shifts in caregiving tasks, alterations in the relationship between the carers and the people they care for, and transformations in the carer's identity. The duration between phases in a carer's journey across the caregiving continuum can vary greatly, and the process is rarely linear. The one consistent aspect of caregiving is that carers frequently encounter substantial distress during role transitions and require tailored support strategies to mitigate the effects of caregiving distress and build resilience.

Given these factors and our learnings from the workshops, we propose a multi-component alternative pathway for carer support (Figure 5). Following this path, we envision a 'Carer Box' which provides critical, localised information while self-identifying as a carer. The resources inside are tailored to the carers' postcode area and the care they provide, corresponding to our service concepts. As timely services, early in the journey, group sessions to support those with growing caregiving burdens. Further, along their journey, drop-in sessions would also support carer management over the long term alongside the challenges of grief.

⁷Montgomery RJV & Kosloski KD. Pathways to a caregiver identity and implications for support services. In: Talley RC, Montgomery RJV (eds) Caregiving across the lifespan: research, practice, policy. Springer, New York, pp 131–156. 2013

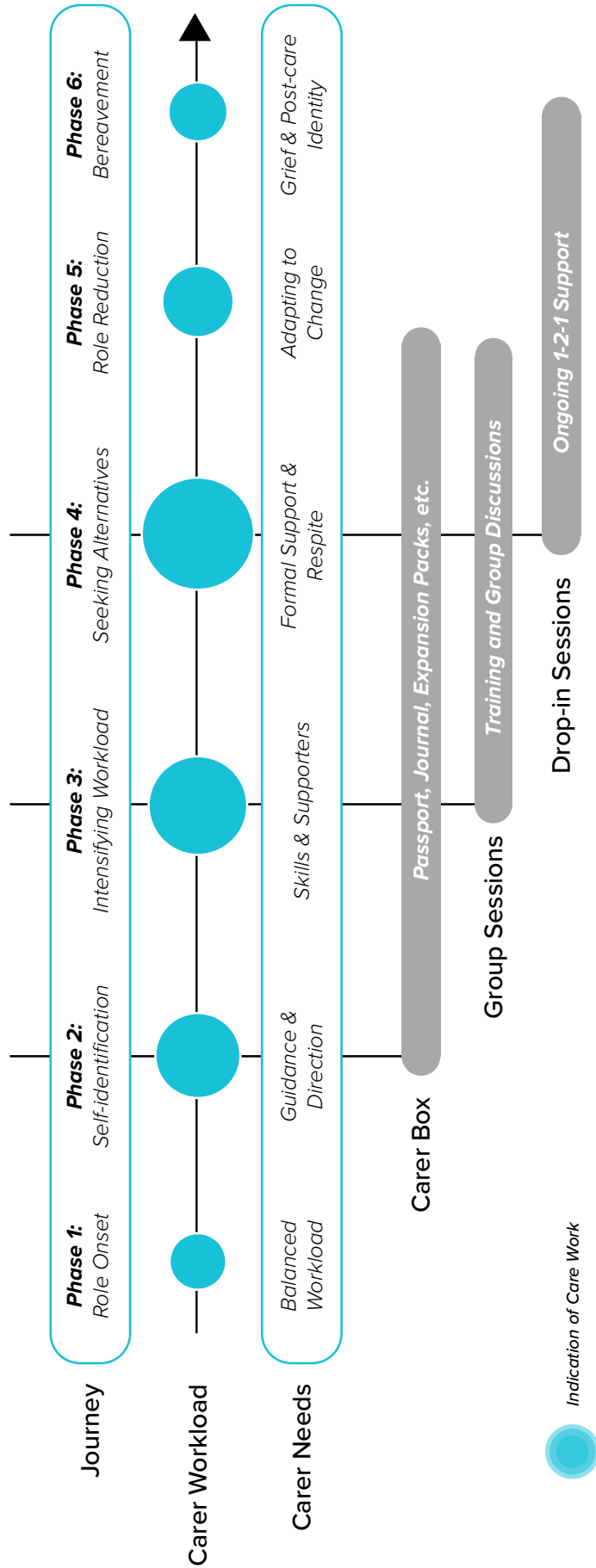


Figure 5: Carer Alternative Support Pathway Prototype

Prototype Feedback: Resources

After designing several support concepts, the researchers produced and shared draft resources and materials for review with participants (Image 3). A prototype feedback session (Image 4) saw participant groups explore and critique more concrete concepts, helping to refine initial ideation into functional and useful forms.

These resources were collated into a **Carer Box** that served as a container and vehicle for information delivery. The box was inspired by the Scottish Baby Box (as described on page 11), which the participants wanted to adapt as a positive way to begin the care journey. Personalising the boxes with information on local services was seen as beneficial. As a vehicle of delivery, the following elements have been co-designed for inclusion in these boxes:

The **Carer Passport** is a document created to efficiently capture and share essential information about a carer's situation, including personal details, information about the person they care for, emergency contacts, and any pertinent health or living conditions. Its purpose is to facilitate communication with health services and ensure that essential information is readily available when needed.

The small size was well-received, with most considering it useful for community care and hospital visits. Carers did seek additional contact information, such as for the care agency they use, alongside additional space to detail specific conditions and medications. Adding these extra pages was essential to those with

multiple care needs or complex treatment regimens.

The option to have handwritten or printable templates was also suggested, as was incorporating a bright red colour for finding in a bag or folder.

The **Wellbeing Cards** are a guide for carers on maintaining psychosocial, emotional and physical wellbeing. Carers emphasised understanding wellbeing as a fluctuating state influenced by thoughts, actions, and experiences. The cards provide tips on emotional and psychosocial support, self-care, stress management, health and safety, and practical advice. They also suggest mindfulness techniques and focusing on the circle of control to improve mental health and reduce stress. General comments indicated more crafty-based prompts and smaller-sized cards to keep in a bag or pocket.

The **Carer Journal** is a document developed to help created to help individuals track their physical wellbeing, mental health, thoughts, emotions, and stress levels over a week and month. It details various caregiving roles within a network, such as assistants, monitors, and outsiders, and encourages users to reflect on their caregiving experiences and personal wellbeing. Carers had mixed feelings about the journal and desired it to be made optional and a log rather than a diary. For example, carers from South Asian backgrounds suggested voice recordings would be better than written accounts, while the other group sought space for problem-solving notes.

The “**Ready to Care**” leaflet is an informational resource for crucial information for carers, detailing their rights, available support, and resources. It defines a carer as someone who assists an unwell, disabled, or older adult without payment or volunteering. The leaflet outlines carers’ rights under the NHS and local authorities, including support plans and access to information services.

Personalised by address, it highlights various support services such as emotional aid, respite care, training, and financial assistance through organisations like Carers Trust and Turn2Us. Additionally, it mentions local carer centres that offer practical support and specific resources available in Edinburgh and Midlothian. Sections on power of attorney, capacity

to consent and self-directed support were requested, with general finance and medical details perceived as useful. Carers also sought further information on respite opportunities, such as at-home support and trips away.

Further personalising the box, the **Expansion Packs** cover topics carers might face in particular circumstances, such as frailty, multimorbidity, and incontinence management. Feedback indicated that information on manual labour, moving, and handling would be helpful, as well as other tasks conducted by formal carers as part of paid work. Carers found the information and directions helpful and appreciated the ability to pick and choose.

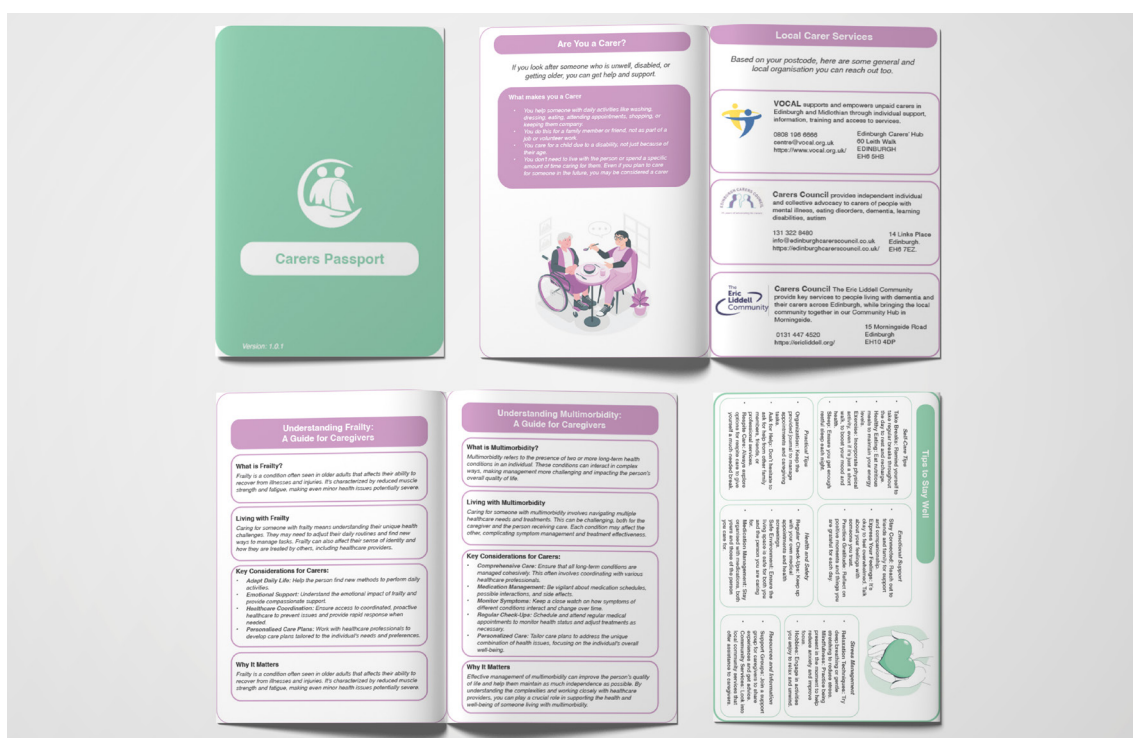


Image 3: Carer Passport, Local Guide, Information Leaflet, Wellbeing Cards (Clockwise)

Prototype Feedback: Services

Alongside the resource materials, we developed service concepts for organisations supporting carers. These aided in addressing earlier input around the individual and support for those already on the carer journey.

Educational Group Sessions: are in-person sessions which seek to increase knowledge and raise awareness of carer roles and caregiving skills. Materials used in the sessions include topic briefs and training resources from Social Care TV⁸. Facilitators require or should have a broad knowledge of caregiving topics, with the opportunity to involve guest facilitators. Participants discussed how the carer journey stage and age-based groups might effectively segment sessions, providing more relevant and helpful information. Series on caregiving skills like manual labour (moving and handling), welfare programs such as self-directed support, and specialist topics such as incontinence management would see greater uptake.

Individual Drop-in Sessions: are face-to-face sessions which aim to provide emotional support, teach stress management and self-care techniques, and encourage carers to prioritise their health. These sessions would occur twice a week, each lasting 2 hours. Facilitators for these sessions would require mental health training and active engagement with the local community. In feedback, participants sought information on respite and caring if participating in these sessions. They also noted several barriers to service uptake: the timing of weekly sessions, their location, and the skills and experiences of facilitators.

⁸<https://www.social-care.tv>



Image 4: Workshop 4 Session at Open Door

Key Learnings

Increasing Need for Tailored Support:

Our workshops reinforce early research by illustrating an urgent need for accessible, tailored support services for informal carers. As the UK population ages and experiences increasing MLTC, participants illustrated common barriers to accessing support and addressing the health challenges of vulnerable older carers. Specifically, difficulties reconciling being both a carer and in need of care were prominent and made realising formal support complicated. As we detail, alternative support pathways through community organisations, including adult day-care centres, may better connect with everyday needs and engage with the complex realities of giving and receiving care.

Adult Day-Care Centres as Critical Hubs:

Adult day-care centres provide essential services for people with MLTC and offer crucial respite and resources for their carers. In collaborating with day-care staff and users throughout these workshops, we have explored their potential role in delivering localised and adaptive interventions. Recognising their remit within the community for care and support, participants saw the importance of adult day-care centres as critical hubs that can enhance carers' well-being and provide ongoing skills and support.

Co-designing Support Tools with Carers:

Involving carers in co-designing support interventions ensures that the resources are practical, relevant, and responsive to the real-world challenges carers face. This participatory approach may lead to more effective and targeted solutions by facilitating participants to map their challenges, explore existing resources and services, and become actively involved in the ideation process.

Importance of Personalised Resources:

Carers may have typical stages to their journeys; however, their circumstances, health, and capacity to care can vary substantially. Tailored interventions that consider carers' needs and cultural contexts and are actively made available and accessible are critical for maximising the positive impact of support services. The Carer Box provides an effective model for delivering personalised and easily accessible informational support and self-care tools, collating health-specific and locally relevant resources.

Addressing Carers' Mental Health Needs:

Carers often face significant emotional stress, which, as we captured throughout the workshops, can negatively impact their mental health. It was evident across participants in workshops 1 and 2 that the historical stigma and embarrassment that came with these conditions were reducing, as individuals felt comfortable highlighting their struggles and discussing the stressors, pain, and difficulties found across their caring journeys. In seeking proactive and ongoing support and psychosocial interventions, they sought access to one-to-one counselling sessions to reduce stress, build resilience, and improve carers' emotional wellbeing. These services were seen as essential further along their journey; however, the more proactive and frequent the support, the better their outcomes.

Enhancing Multimodal Support: A

multifaceted pathway approach reflects the diverse needs of carers, providing much more person-centred solutions and better engagement in support services. Such systems see one or more types of support offered simultaneously, fitting into people's lives more effectively and providing multiple options to help tailor it. Our workshops focused on building a multimodal pathway, combining personalised resources through a Carer Box with an educational and psychosocial community-based intervention to ensure a more comprehensive support system for carers. Future efforts should integrate various forms of support to create a multifaceted approach to caregiving challenges.

Conclusion

What's Next?

The prototype will undergo an iterative refinement process, engaging a diverse group of informal carers to ensure this alternative pathway of support addresses the diverse needs and challenges that carers and care recipients face in different contexts. Following this refinement phase, the intervention will be pilot-tested in adult day-care centres across Scotland. This future work will allow community organisations, including adult-day care centres, to evaluate the intervention's real-world applicability, acceptability, practicality and potential effectiveness.

Acknowledgments

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