



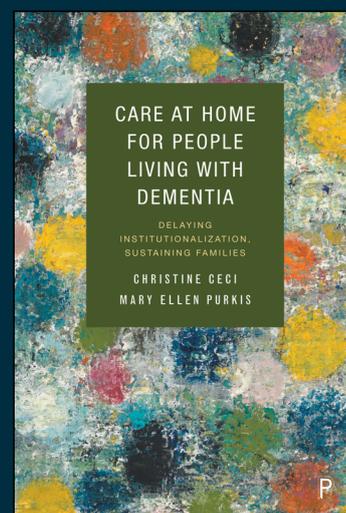
## PLANNING FOR CARE

### OVERVIEW

Ethnographic research has the capacity to demonstrate the critical distance between policy and everyday life – this is not surprising but it can be learned from to reshape approaches to policy.

This book – a field study of everyday practices of care for people diagnosed with dementia who live at home – shows the limits of prescriptive, macro-level approaches to dementia planning. The attraction of such planned approaches is that they promise to stabilize big, complex, population level problems such as dementia. Fulfilment of that promise rests on a regimentation of care that can transform the home into something like a satellite care facility. Additionally, while ‘diversity’ among people is sometimes acknowledged in policy, focusing on everyday practices as we have in this book shows that it is the specificity of daily life that matters for care but often there is tension between home and system. It is this reality that is often overlooked in policy.

Rather than planning towards numbers of people anticipated to develop dementia in the future, we advocate for policies that enable planning for care. Planning for care makes room for the improvisation and ‘patchwork’ solutions that are most needed on the ground. Our recommendations stand in contrast to those models that assume care can be packaged and delivered by interchangeable personnel. As such, our recommendations risk being misunderstood as too personalized and unique for broad implementation. However, our study illustrates how efficiencies assumed as part of general, ‘ideal’ programs, actually generate additional work for families – creating the risk that costly care programs may be ignored or experienced as failing to meet the needs of families.



*Care at Home for People Living with Dementia* by Christine Ceci and Mary Ellen Purkis is published by Bristol University Press, September 2021

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## CONCLUSIONS

Home-based care for people living with dementia has led to the emergence of the family home as both a site of care and as a solution to a health care system perceived as overwhelmed by demands. This is a deeply problematic and contested conception of home. As a site of care, home becomes a workplace for professionals but at the same time, it continues to serve as a place where families try to live their lives.

Four practices shaped the work of professionals and the lives of families in our study:

- **Navigation:** A complex activity arising from an assumption that problems faced by families in accessing services is a problem of a terrain not well enough mapped. Navigation work is primarily focused on by health service administrators seeking to reduce what appears as overlap and lack of coordination. There was no evidence that efforts at creating navigation systems made it easier for families to access help.
- **Sustainability:** Health care leaders advocate for 'partnership' with families as a way of sustaining health systems. These partnerships, however, are designed to reduce the likelihood of the system being overwhelmed. Families, by contrast, are interested in sustaining a liveable life, and accept assistance that helps with this. There was no evidence of synergy between these two distinct interests in sustainability.
- **Patterning dementia:** Families developed a sense of illness trajectory by adopting the conceptualization of dementia stages discussed at medical appointments. Health professionals attached specific care practices to these stages largely focused on risk management. By contrast, families used the idea of stages to work out how much time remained for important family events. There was no evidence that the differences between these ideas of patterns in the dementia trajectory were ever examined. Rather than a singular 'dementia trajectory', there were multiple pathways walked and woven by families.

- **Care at home:** Ultimately, disregarding borders between professional care practices and those instituted by family members comes to transform the home into an extension of the formal care system. Such transformation is experienced by family members as care they need to work around rather than as helpful to them in their own efforts to support their family member.

Each of these practices illustrates disregard of the border between professional caring and practices of living at home with a person diagnosed with dementia. The failure to observe the borders obscures resourcefulness of families in caring for and adapting to changes in their family member's needs over time. Our research also revealed moments when borders were less evident, undisrupted and even respected. At such moments, other practices were revealed and we note two such instances here:

- **Helping:** What helps cannot be pre-determined. Families did find offers of support helpful at moments when they were seeking out assistance and when an offer of help responded to the conditions present at the moment of the troubles being encountered. For help to be experienced as helpful, both proximity and an understanding of context are necessary.
- **Patchwork:** Care practices rely on sensitivity to difference in the here and now. Our study revealed instances where programs and plans for families were patched together by those formal care providers closest to families because they tried to help with the problem that was there in the moment of encounter.



## POLICY RECOMMENDATIONS

What families in our study showed us was that care offered at a time when they most need it is when they experience being helped. This may sound obvious but much formal care provision disregards this fact. Formal care providers require greater proximity to people's homes, increasing opportunities for being present when troubles arise. These providers must be empowered to exercise local knowledge and discretion to engage in help that supports and extends the efforts of families.

Our policy recommendations are built on these findings and focus on re-conceptualizing how personnel and material resources are deployed in community settings. That is, in addition to planning for numbers of people requiring assistance, policy makers must also create policy that supports the conditions through which care can occur.

Here we keep in mind the situation to which a policy of planning for care must respond: to a large extent the troubles facing families cannot be 'fixed' but there is a question of whether and how they could be improved. Prescriptive approaches cannot meet families where they are as they work continually to relate to new situations, evaluating what needs to be done, adapting, accommodating that which has not been, and possibly cannot be, planned for. Thus there is not a 'best' practice to be aimed for, as this implies a singular approach, but rather space must be created for good practices.

Policy should be informed by values that assert the centrality of care: the practices and flow of everyday life at home must be respected. Homes should not become satellite care facilities. Changing our approach to families who provide care for someone diagnosed with dementia demands different responses from health care leaders, health service managers and frontline care providers. But in each case, planning for care as well as planning for numbers, requires a 'patchwork' approach to policy that would:

1. Recognize greater plurality in what might constitute help for families and a better understanding of where tensions, as well as synergies, may arise between home and formal care systems.
2. Challenge the logic of prescriptive, programmatic practices currently organizing health and social care.
3. Support families and providers to work together as allies, rather than providers or recipients of services – this respects the distinct practices of each. In contrast to delivering services to families, allied practice means sustaining families by supporting them in their caring practices. Allied practice means being curious about what works for families and finding ways of extending that in support of family care.

Thus the role of policy is to create a workplace environment that enables frontline practitioners to:

- gain proximity to families providing care, and
- use local knowledge and discernment in responding to the care issues of the moment.

This approach to the workplace environment relies on:

- increased numbers and types of workers with adequate knowledge of local conditions and resources;
- increased time for frontline workers to get to know families through smaller case or client workloads, and a flexibility in deployment that allows for regular contact;
- access to a wider range of services such as community-based day programs, respite services, occupational health services, and nursing services with the caveat that the match of these services to the needs of family members in the 'here-now' moment is what renders such services helpful.

## About the book

What 'kind' of community is demanded by a problem like dementia?

As aspects of care continue to transition from institutional to community and home settings, this book considers the implications for people living with dementia and their carers.

Drawing on extensive fieldwork and case studies from Canada, this book analyses the intersections of formal dementia strategies and the experiences of families and others on the frontlines of care.

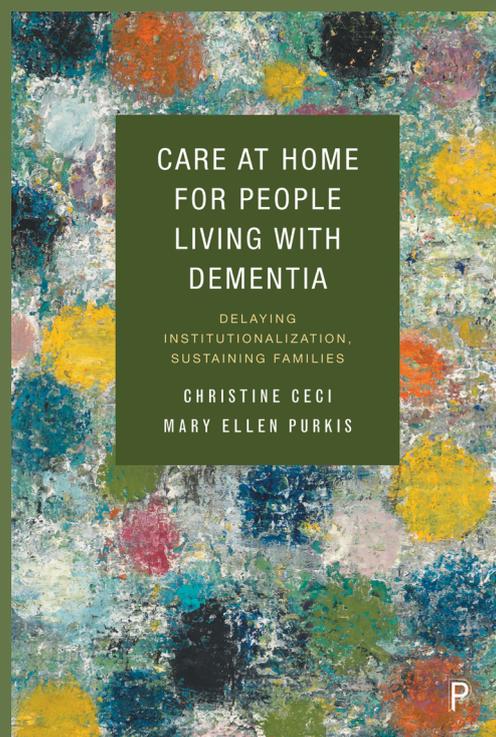
Considering the strains placed on care systems by the COVID-19 pandemic, this book looks afresh at what makes home-based care possible or impossible and how these considerations can help establish a deeper understanding necessary for good policy and practice.

*"This is an intriguing and thought-provoking ethnographic style book that brings questions to our understanding of family care practices. The everyday experience of family members is brought to the fore in a novel way."*

**ANTHEA INNES, UNIVERSITY OF SALFORD**

*"The burning issue in this book is how to support care at home. Adopting a practice-based research approach, it offers important insights sorely needed across fields and to everyone involved in care for people living with dementia."*

**INGUNN MOSER, VID SPECIALIZED UNIVERSITY/DIAKONHJEMMET UNIVERSITY**



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