

Informal Care as a Challenge



The provision of informal care can add massively to the social and economic well-being of a country.¹ Yet carers themselves may need considerable help and support. Many of these reflections have become even more vivid in 2020 as people needing care, and their carers, have experienced together the first stages of a global pandemic. In order to understand carers' need for help and support and the challenges they face, it is important to define who informal carers are and what they do.

Social carers: definitions and types

It is important to think about the need for social care from the perspective of the individual who needs support (called here the “care recipient” or alternatively the “person in need of care”).⁷

Social care is largely about assisting with people's personal and practical help for activities of daily living so that they maintain their independence.

The 2019 directive on work-life balance describes carers in the following way: “carer’ means a worker providing personal care or support to a relative, or to a person who lives in the same household as the worker, and who is in need of significant care or support for a serious medical reason, as defined by each Member State.” (Article 3 - Definitions, p.23).

The 2019 directive does not appear to be entirely clear about the situation of family carers who live in other geographic locations to their loved ones (whether nearby or at a distance), and also emphasises the need for care or support to individuals “for a serious medical reason”.

As a consequence, attention should be paid to the following four key points, where more clarity may be needed:

- Medical conditions and definitions may differ according to Member State.⁸
- Carers do not always live in the same household as the person needing care and support, and may live at a substantial geographic distance.
- The care or support needed may be non-medical.
- While the directive refers to implications for people who work in small and medium-sized enterprises, it makes no reference to the role that information technology can play in the care process, although it does refer to telework options being allotted/allowed in certain jurisdictions (in 2019, in three Member States).

The CareWell project has provided a useful glossary of terms⁹ relevant to social care and has classified the people giving care (e.g., to support frail, older adults) into two types, informal and formal carers:

- Informal carers: people who are chosen to support the care recipient and/or who are related to the care recipient. In this first case, CareWell refers to caregivers who may be e.g., a family carer or a friend/neighbour or a volunteer.
- Formal carers: other types of carers e.g., health care professionals, social care professionals, health care support workers, care support workers, and care co-ordinators.

Challenges

Many of these roles are currently provided without support from information and communication technologies (ICT), and – indeed – some roles could in conventional circumstances continue to be offered without ICT support, since they refer to practical activities of daily living.¹⁰ Nevertheless, especially in relation to data and information, it is widely acknowledged that ICT can offer more timely information support e.g., through the existence of, and interaction with, electronic health records/personal health records and/or social care records as well as shared integrated care records (which bring health and social care records together). In addition, in terms of the relationship between the two types of carers, informal carers are often the ones who detect early signs of alerts or risks of adverse health outcomes on the part of the patient: by using digital support, these alerts could be transferred between, among, or from informal carers to formal carers.

Importance of Informal Carers/Personas for Transforming and Supporting Person-centred Care



Lives can be complex, and the support or help needed by a person/persona may differ at various stages throughout their life-course. The European Innovation Partnership on Active and Healthy Ageing (EIPonAHA) has developed a number of personas,⁴ and associated narratives, that focus on a set of people's health and care needs and identify the kinds of digital solutions currently available to them and their “circle of care”. The solutions identified have both immediate applications and also indicate future directions.

This guide on the support needed by individuals and their informal carers emerged from a concern within the EIPonAHA Blueprint team to ensure that there should be an expansion of the personas/narratives and scenarios towards challenges reflecting their quality of life, activities of daily living, and physical and mental wellbeing (rather than simply concentrate on medical or clinical issues).

These notes offer pointers regarding some issues related to social care that should be kept in mind in terms of digital interventions related to integrated care, when further developing personas, narratives, and associated user scenarios.

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Six questions that include a focus on social care

EIPonAHA Blueprint team members working on developing personas/scenarios started to consider six questions on social care. For example:

- What kind of social care help, if any, does the individual persona need?
- Who is offering, or who will offer, this social care (e.g., a household or a family member; friend; a volunteer; a formal carer)?
- What kinds of skills, and skills profiles, do carers need (including digital skills)?
- Are digital solutions currently available to help provide this social care?
- Are these digital solutions accessible?
- What kinds of digital solutions might be useful in the future?

It was suggested to the Blueprint team that the ADVANTAGE Joint Action and the Facing Frailty campaigns provide an example of a stage in the life-course where carers can use digital technologies, where the above six questions would be applicable. In addition, these questions were the source of inspiration for discussions held in a AAL/Conference of Partners workshop in Aarhus, Denmark, in September 2019,⁶ in particular for a joint event on the Blueprint personas and SHAFE project for Smart Healthy Age-Friendly Environments, please also see our guide on Smart Homes if this topic is of interest.

Key Issues Regarding Care Recipients and Informal Carers



Generic issues

A possible list of issues that a care recipient might need to bear in mind could include:

- Types of care that are needed and the way the care could be accessed or financed.
- Types of care assessment that need to be undertaken, both formally and informally.¹¹
- The extent to which family members/relatives can assist with care or whether more formal care support is needed.
- Whether needs for care may alter over time.
- How informal carers can connect, e.g., digitally, with formal carers.

In addition, the Blueprint team members added three other issues, such as:

- Maintaining the quality of life of the care recipient.
- Managing the symptoms of the particular disease/condition.
- Assisting with (or undertaking their own) health promotion or health management activities that can be carried out at home and be digitally supported (examples include adapted physical activity, memory training, and serious games, so as to maintain their own good health if they restricted at home).

A possible list of issues that caregivers (of various sorts, but especially family carers) may need to bear in mind, include:

- The financial implications of caring.
- Changes in roles among family members (e.g., physical, mental, emotional, or sexual).
- Changes in employment as a result of giving care (e.g., the degree of support given by employer).
- Changes to the caregiver's own mental state (i.e. carers may be prone to depression).^{12,13}
- The individual's ability to provide care by:

Learning how to do certain tasks for the care recipient (e.g., preparing food, changes in food consumption/nutritional needs,¹⁴ serving food; washing/bathing; toilet needs; preparing for bed).

Understanding certain needs (e.g., what medication is needed - at what times and in what dosages; what kind of lifting or help with mobility might be needed).

Understanding the particular [medical] condition that the care recipient is experiencing, and its medical or clinical implications (e.g., complexity in different forms of dementia).

Managing or organising the care needed from a practical perspective.

Accessing respite, to enable carers to recharge and gather strength essential to continue the care essential for informal /family carers. Carers need to be informed as to how they access respite and support services.

Formal carers and formal care services

Carers and their associations/bodies may be concerned about such issues as:

- Policy,
- Research,
- Useful (reputable, accredited) information and publications,
 - o Personnel receive training in care and how to conduct it (they are often accredited or certified).
 - o Personnel often perform their work according to precise guidelines/guidance. Higher levels of management may well check their performance.

Integrated Care

The lack of integration between different care services is often problematic. It means that, to a greater extent that if services were to be integrated, the burden of sharing information and maintaining records is placed on the carer.

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Supporting Mechanisms and Tools that Help Address the Topic



Digital solutions for caregivers

In terms of digital solutions, in addition to the way(s) in which a care recipient's electronic health record or electronic social care record might be accessed, care and consideration could be given to both care recipients' and caregivers' needs related to:

- Information about changes in needs and changes in roles,
- Practical help,
- Practical training about how to give help (food/nutrition),
- Mobility,
- Terms and conditions relating to e.g., finance; banking; travel.

The provision of this information in easy and simple ways should be considered (whether in terms of literature; websites; blogs; or videos). It is probably also important to consider the need for communication among "circles of caregivers" i.e., between family members, including different generations of families (e.g., mobile apps that can be shared; and/or subscription to either electronic or paper-based newsletters).

Volunteer carers: Some observations

In a number of European Union Member States, there is a tradition of voluntary associations having been established that offer help and support.

- Volunteers can be arranged with various local or national voluntary services to e.g., drive people to their destinations, if they cannot easily travel on their own; pick them up and accompany them to activities/events; be present with them to undertake certain tasks or activities e.g., reading, playing board games, holding conversations; helping in search for particular information.
- There may, however, be regulations about certain activities that volunteer carers cannot undertake (e.g., searching for financial information, doing online banking, assisting with the taking of medicine).

Digital solutions for volunteer carers

Here, consideration could be given to the kinds of activities that volunteer caregivers can offer, for which electronic support might be useful. Many volunteer services can be found online e.g., AGE UK. Certification, either for the services and/or for the volunteer caregivers, may be needed and could possibly be acquired online.

Specific examples of solutions include:

- In-home "assistance" or "presence" through various speech recognition systems/ "social robots" currently offered by many large-scale digital providers (often not geared specifically to care needs but considered potentially to offer companionship or responses to enquiries).
- Security and alarm services, whether e.g., provided as classic wrist-based or pendant-based alert systems or more sophisticated home-wide automatic door opening/closing mechanisms.
- Online information offered via useful online websites.
- Appointments alternatively to be offered as videoconferences, if attending visits or meetings in locations other than their home would be too difficult or onerous for the person and/or visitors could attend a meeting e.g., in the person's home from a distance. (No judgement is made here about whether the subject of the meetings/visits are about e.g., communication; companionship; advice; guidance; medical advice.)
- Online training (for a range of needs). Could take place in the format of a video rather than written documentation; support via 'virtual consultations', support via apps.
- Support for "care circles" via apps (such as WhatsApp).
- Technology-based options such as medication reminders, remote monitoring.

Examples of Apps to support carers (UK focused)

- "Jointly" (an app provided by Carers UK). This app helps people to create a "circle of care". It was started and designed by carers for carers. It helps family and friends who are caring for an individual to keep in contact and inform each other about developments. It costs very little. Some forward-looking employers are offering it free of charge to their employees: <https://www.carersuk.org/help-and-advice/technology-and-equipment/jointly>.
- Carers UK. Some digital resources are available, e.g., this is Carers UK digital platform: <https://www.carersuk.org/for-professionals/digital-resource> with its descriptions of resources including documentation on "What can tech do for you?", complete with documentation and a video: www.carersuk.org/tech, <https://www.carersuk.org/help-and-advice/technology-and-equipment/tech-for-you>.
- NHS Choices (social care and support guide). On the social side of NHS Choices, the portal provides nine separate areas of guidance and support for people who are carers e.g., about financial issues, making decisions including difficult decisions, practical tips, and what help and support is available in the public arena: <https://www.nhs.uk/conditions/social-care-and-support-guide/>.
- Age UK (general information). "[G]rowing older does not come with a manual". A page on the portal provides free information about five areas, include care and support: <https://www.ageuk.org.uk/information-advice/> and <https://www.ageuk.org.uk/information-advice/care/> (e.g., arranging social care, paying for care, problems with care, looking after someone else, housing options).

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Digital solutions for formal carers and formal care services

Here, consideration could be given to the kinds of information that formal carers need, and for which it might be useful to receive electronic support. Examples include:

- The need for more formal information about rules and regulations and policy positions.
- Empirical evidence offered through research documentation.
- Access to documentation about training as well as training itself.
- Personnel and management may need to be in contact, as well as seeking for care with the care recipient's "circle of care" (e.g., family members).
- Given technological developments, digital systems and services that are interconnected (e.g., via the Internet of Things, machine learning), more sophisticated service/alarm systems and/or in-house based monitoring services could potentially be used.

Non-digital tools (e.g. policies)

On 13 June 2019, the European Council adopted a directive on work-life balance for parents and carers.² Two areas of the directive are relevant to care and carers:

- Carers' leave: This is a new concept at European Union (EU) level for workers caring for relatives in need of care or support due to serious medical reasons. Carers will be able to take five working days per year for this purpose. Member States may use a different reference period, allocate leave on a case-by-case basis, and may introduce additional conditions for the exercise of this right.
- Flexible working arrangements: The right for parents to request (flexible) working arrangements has been extended to include working carers.

Thirteen non-governmental organisations, such as AGE Platform Europe and Eurocarers, commented on the importance of this directive. Their comments included seven tips for the future (relating to European funding programmes and e.g., a European Work-Life Balance Index). They encouraged Member States to transpose the directive's conditions into force rapidly (the Member States are to do so within a period of three years i.e., until 31 July 2022).³

While the directive focuses on the availability of leave and the flexibility of working arrangements, there are many more issues and challenges related to social care and informal care that will need exploration in the future – the 2020 experience of people needing care and their caregivers exacerbates the need for such a review.

Main Stakeholders Concerned



- Care recipients.
- Informal carers (e.g. family carer or a friend/neighbour or a volunteer).
- Formal carers (e.g. health care professionals, social care professionals, health care support workers, care support workers, and care co-ordinators).
- Voluntary and state care-based organisations and foundations.
- Digital solution producers.
- Policy makers.

References and Guidance Documents



1. Unpaid carers save the UK £132 billion a year – the cost of a second NHS: <https://www.carersuk.org/news-and-campaigns/news/unpaid-carers-save-the-uk-132-billion-a-year-the-cost-of-a-second-nhs>
2. Better work-life balance for parents and carers in the EU: <https://www.consilium.europa.eu/en/press/press-releases/2019/06/13/better-work-life-balance-for-parents-and-carers-in-the-eu-council-adopts-new-rules/>
3. See Eurocarers factsheet and position paper on work-life balance: <https://eurocarers.org/publications/the-work-life-balance-directive-what-is-in-it-for-carers/>, <https://eurocarers.org/publications/reconciling-work-and-care-the-need-to-support-informal-carers/> and <https://eurocarers.org/product-category/position/>
4. Blueprint on Digital Transformation of Health and Care for the Ageing Society: https://ec.europa.eu/eip/ageing/blueprint_en/
5. The Face up to Frailty campaign: <http://advantageja.eu/index.php/news-titolo/news/501-the-face-up-to-frailty-campaign-begins>
6. Smart Healthy Age Friendly Environments and the Blueprint for digital transformation of Health and Care (workshop 8): <https://www.aalforum.eu/about/programme/workshop-8-smart-healthy-age-friendly-environments-and-the-blueprint-for-digital-transformation-of-health-and-care-joint-session-aal-eip-on-aha/>
7. Social care is described well and briefly by Caroline Abrahams, AGE UK's charity director in a one-minute video interview: <https://www.ageuk.org.uk/information-advice/care/arranging-care/> (see "What is social care?" and YouTube).
8. Scaling up the univocal Identification of Medicinal Products: <https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/opportunities/topic-details/sc1-dth-09-2019?>
9. CareWell project work package 8: 25th November 2016, v0.4: "Glossary of terms: Terms with descriptions for use in CareWell final deliverables". The CareWell project focused on developing integrated healthcare services, facilitated by information and communication technologies (ICT), to serve the needs of frail, older population groups with multiple chronic conditions. It also drew on

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the findings of two earlier projects (SmartCare and BeyondSilos) that had dealt with the integration of social care. The terms in the CareWell glossary were validated by a range of social care experts.

10. Examples include using the telephone, managing money, or shopping for groceries. They are described as tasks that permit the care recipient to “live independently in the community”.

11. The ways of assessing whether more formal (social) care is needed differ throughout Europe.

12. This is especially the case because caregivers can experience what is known as the “caregiver burden” (negative health outcomes for themselves due to the pressures of providing care): <https://jamanetwork.com/journals/jama/article-abstract/1840211>;

<https://jamanetwork.com/journals/jama/article-abstract/1104895>

13. Examples include both mental effects on formal caregivers and informal caregivers (in a variety of countries, including China):

<https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-017-4563-6>

14. Implications of changes in diet of the care recipient, not only for the individual concerned but also for his/her caregivers or family members; the ease with which a family can switch to another type of cooking or prepare alternative foods.

15. Help for carers looking after a loved one: <https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/>

16. Europe enabling Smart Healthy Age-Friendly Environments: <https://www.interregeurope.eu/eushafe/>

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