

# iSupport for Rare Dementias



Supportive guide for carers of  
people with rare dementias



## Adaptation

This adaptation of iSupport for carers of people with rare dementias was developed with the help of six people caring for someone with a rare dementia and nine healthcare professionals. They kindly spent time reading iSupport and making suggestions on how to make it relevant for people caring for someone with a rare dementia.

### User guide

iSupport has been developed to provide accessible, evidence-based training and information, tailored to carers' needs. It aims to improve knowledge and caregiving skills, such as carers' ability to cope with dementia symptoms and care for themselves. iSupport seeks to enable people with dementia to live in the community while preventing or reducing carer stress. The information included in this guide was carefully designed to help carers cope with the important challenges that they may face when caring for someone living with dementia.

### What is included in iSupport?

This guide is organised into five parts: (1) Introduction to dementia; (2) Being a carer; (3) Caring for me; (4) Providing everyday care; and (5) Dealing with behaviour changes that might happen in people living with dementia.

**Part 1** provides an introduction to what rare dementias are, including what happens to people with dementia and what to do if you think that your family member or friend has dementia. **Part 2** focuses on improving communication, shared decision-making and involving others in caring for the person living with dementia. **Part 3** aims to reduce carer stress by making time for pleasant activities and thinking differently. **Part 4** focuses on eating and drinking, including creating more pleasant mealtimes and preventing health problems, using the toilet and continence care, and personal care. Finally, **Part 5** provides an introduction to common changes in behaviour for people with rare dementias that might be distressing and upsetting for both the person with dementia and you as the carer. These symptoms include memory loss, aggression, depression and anxiety, difficulty sleeping, delusions and hallucinations, repetitive behaviour, walking and getting lost as well as poor or decreased judgement.

## Acknowledgements

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The websites were copied from the online iSupport for dementia programme [www.iSupportForDementia.org](http://www.iSupportForDementia.org), Version 1.0, World Health Organization, Copyright (2018). Adapted and translated with permission of WHO.

## Disclaimer

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