

# Ageing in rare, chronic diseases

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## Age transitions

With more treatments becoming available for people with rare diseases, we will encounter a new problem: due to ageing. A number of patients with rare, chronic diseases have experienced a number of remarkable transitions in their lives. The most important one is from no treatment to good treatment, like in haemophilia about 45 years ago.

Another transition is that during their lives they go from one disease to a number of diseases (co-morbidity) through the natural process of getting older or as a consequence of the side-effects of treatment. These transitions are visualized in the pictures below.



*Haemophilia patients in the 1960's  
a period without treatment options*



*The boys on the left,  
picture 45 years later*

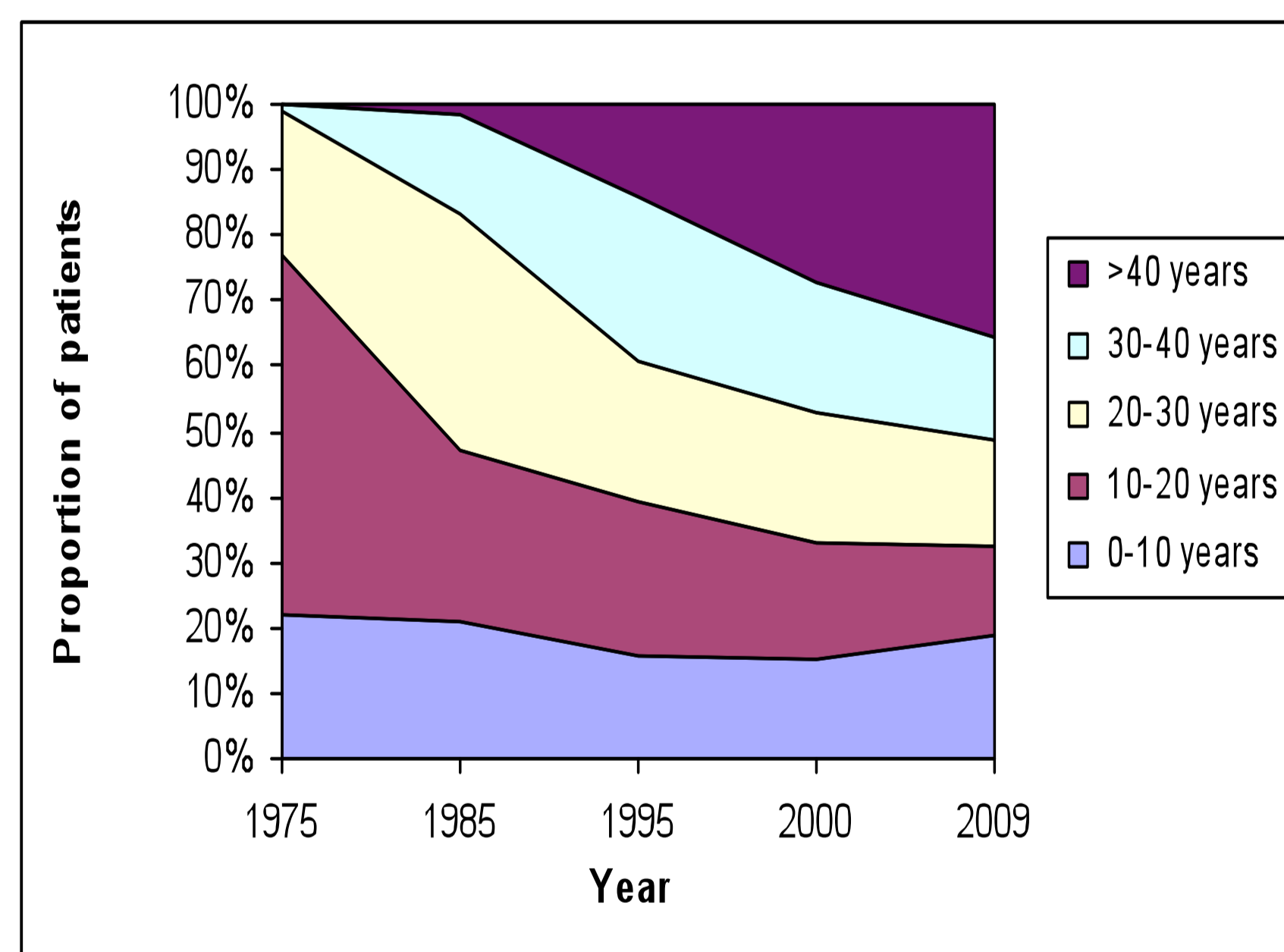


*Haemophilia patients in the 2010's,  
profiting from modern treatment*

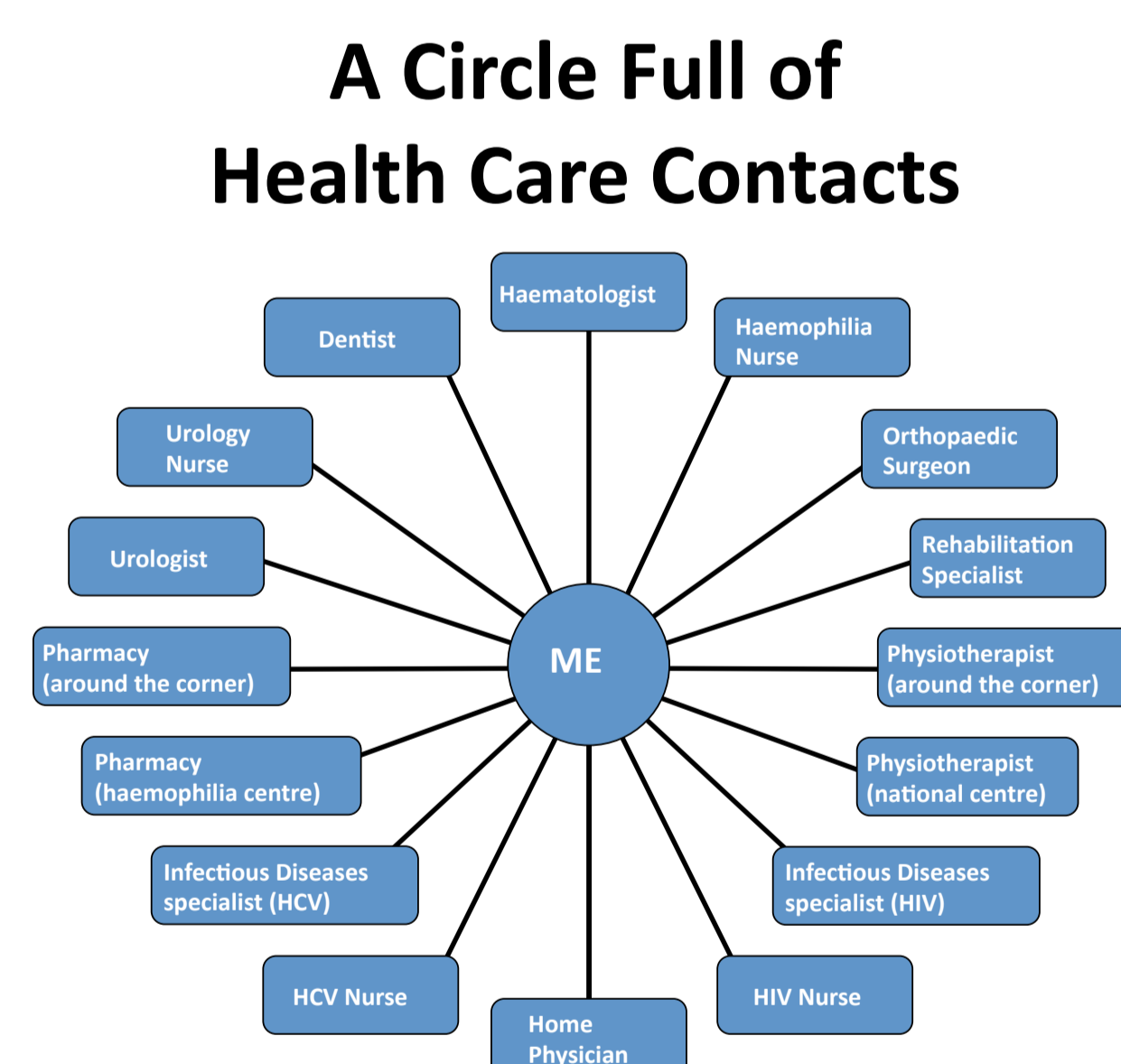
## Ageing-related problems

Becoming older, can create new problems. The first problem could be the lack of co-ordination between different medical specialists and/or paramedical staff. The second is poly-pharmacy – the use of multiple

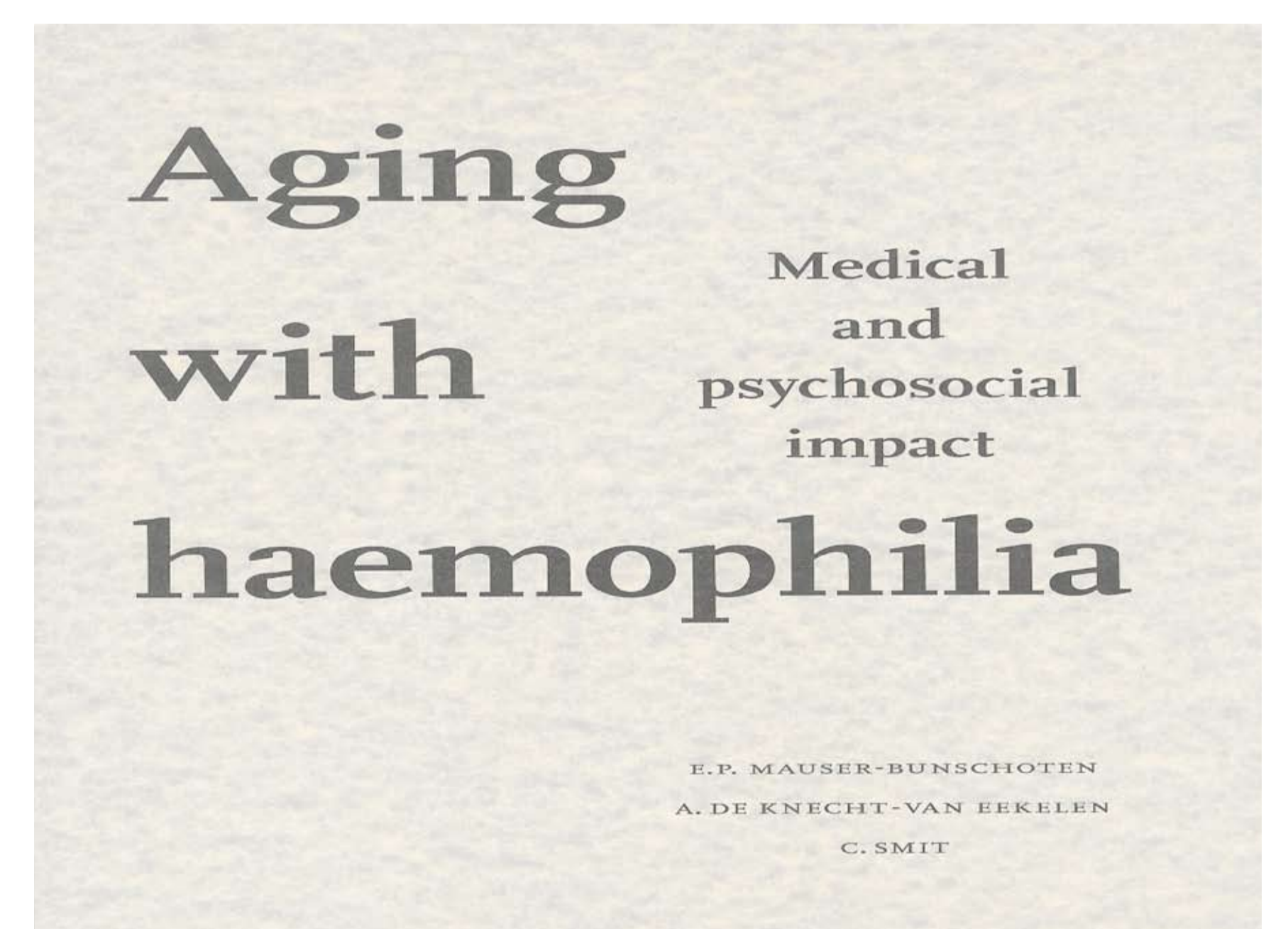
medications and as a consequence of these first two problems a third problem occurs, which is often addressed as the 'fear' factor. The 'fear' factor is caused by the feeling of loss of control by the patients.



*Proportion of patients (%) with severe haemophilia in different age-groups from 1975 to 2009, data from the Van Creveldclinic, Utrecht, The Netherlands*



*Ageing and co-morbidity:  
a circle full of health-care contacts*



*Aging with haemophilia:  
a first book on ageing in rare, chronic diseases  
(published in 2007, ISBN 978-90-731-0802-8)*

## Conclusion

Where more elderly people with rare chronic diseases will gradually transit to nursing homes, more knowledge should be available there to deal with these new groups of patients.

They will differ a lot from the persons who usually live in nursing homes and who develop co-morbidity at an older age.