

The Elderly Hemophilia population

A Nordic patient organization perspective

Background:

The situation for the ageing hemophilia population in Scandinavia has frequently been discussed whenever the Nordic Societies get together. There is a lack of knowledge how ageing affects elderly persons with hemophilia (PWH); among the PWH themselves, their relatives, as well as within the medical health care system, social authorities and institutions. In order to address these issues a project was formed 2011 by the Swedish and Norwegian Hemophilia Societies with support from Bayer AB.

Aim of the project:

To identify needs of elderly PWH and their relatives in Sweden and Norway and to communicate these needs to whom it may concern, such as PWH, relatives, the medical profession and social authorities.

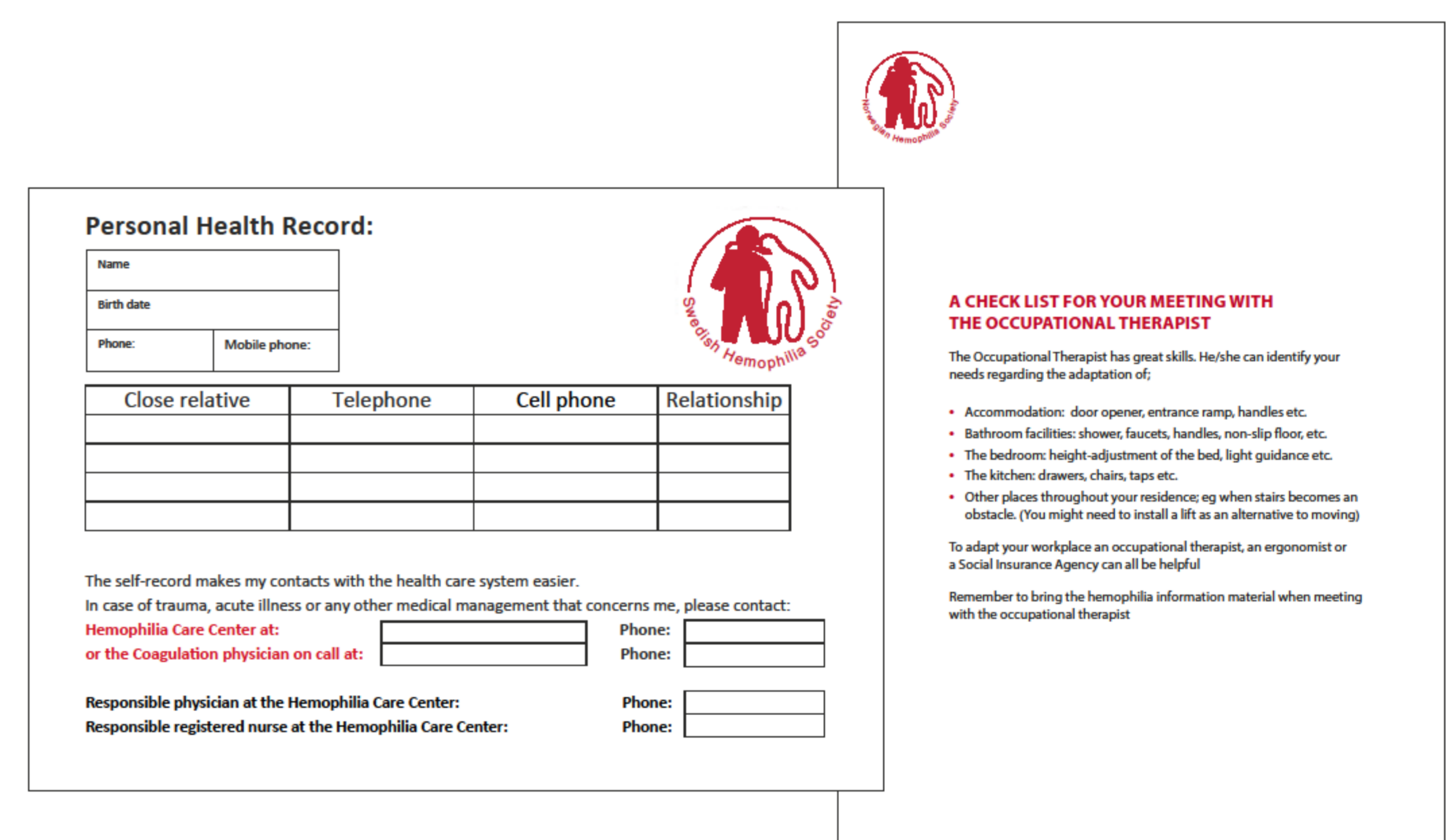
Methods:

Annual gatherings of elderly members and their relatives in both countries serve as reference and work groups. A steering group in each country takes the project forward and communicates results between the two societies. The medical needs of elderly PWH are also subject to cooperation between the Nordic Hemophilia Care within an Advisory Board. The Advisory Board will, when needed, serve as medical back up and have access to results from the project.

Results:

So far the project has resulted in the following material possible to download from the websites of the hemophilia societies:

- A short leaflet "What is important to know about elderly PWH" to hand over in contacts with local medical professionals and social authorities.
- Checklists that make it easier to remember all important things when you visit a physician, social counselors and physiotherapists at the Hemophilia Centers.
- Checklists for use in contact with the local health care, home care, social services, physiotherapist, occupational therapist and retirement homes.
- A Personal Health Record where the patient fills in important information such as diagnosis, other diseases and medication etc. This Record is intended to be used by PWH and their relatives in contact with healthcare institutions and in emergency care.



Personal Health Record:

Name: _____
 Birth date: _____
 Phone: _____ Mobile phone: _____

Close relative	Telephone	Cell phone	Relationship

The self-record makes my contacts with the health care system easier.
 In case of trauma, acute illness or any other medical management that concerns me, please contact:
 Hemophilia Care Center at: _____ Phone: _____
 or the Coagulation physician on call at: _____ Phone: _____

Responsible physician at the Hemophilia Care Center: _____ Phone: _____
 Responsible registered nurse at the Hemophilia Care Center: _____ Phone: _____

A CHECK LIST FOR YOUR MEETING WITH THE OCCUPATIONAL THERAPIST

The Occupational Therapist has great skills. He/she can identify your needs regarding the adaptation of:

- Accommodation: door opener, entrance ramp, handles etc.
- Bathroom facilities: showers, faucets, handles, non-slip floor, etc.
- The bedroom: height-adjustment of the bed, light guidance etc.
- The kitchen: drawers, chairs, taps etc.
- Other places throughout your residence; eg when stairs becomes an obstacle. (You might need to install a lift as an alternative to moving)

To adapt your workplace an occupational therapist, an ergonomist or a Social Insurance Agency can all be helpful

Remember to bring the hemophilia information material when meeting with the occupational therapist

Other work in progress:

- Checklists on pain management, mental health, traveling and the work situation of 50+.
- Identifying and address the needs of relatives to elderly PWH.

The Personal Health Record can be downloaded from this page:

www.fbis.se/wp-content/uploads/Personal-Health-Record.pdf



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