

The art of ageing with long-term conditions

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Behind every patient there is a long history

Ageing, comorbidity and the ‘fear’ factor

The need for coordination & vision
(integrated care)

Key messages

Hemophilia, a rare disease

Characterized by spontaneous bleeding
in muscles and joints
or by trauma (accidents, operations)

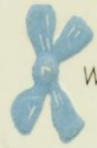
No treatment possibilities before 1965

Hemophilia

Heden werden wij verblijd met de geboorte van ons
zootje en broertje

CORNELIS

M. SMIT-KROON
J. SMIT
en WILLY

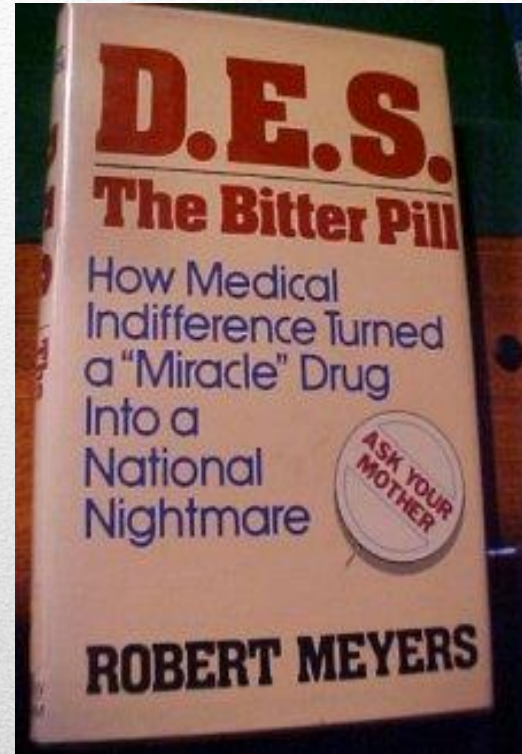


Wij noemen hem KEES

Nieuwe Niedorp,
1 Januari 1951
Laagzijde B 249



A carefree start



A period full of concern



Medical progress 1965-2023



Home treatment



Medical drawbacks

From 'unmet medical need' → good treatment

Haemophilia (70's)

HIV (90's)

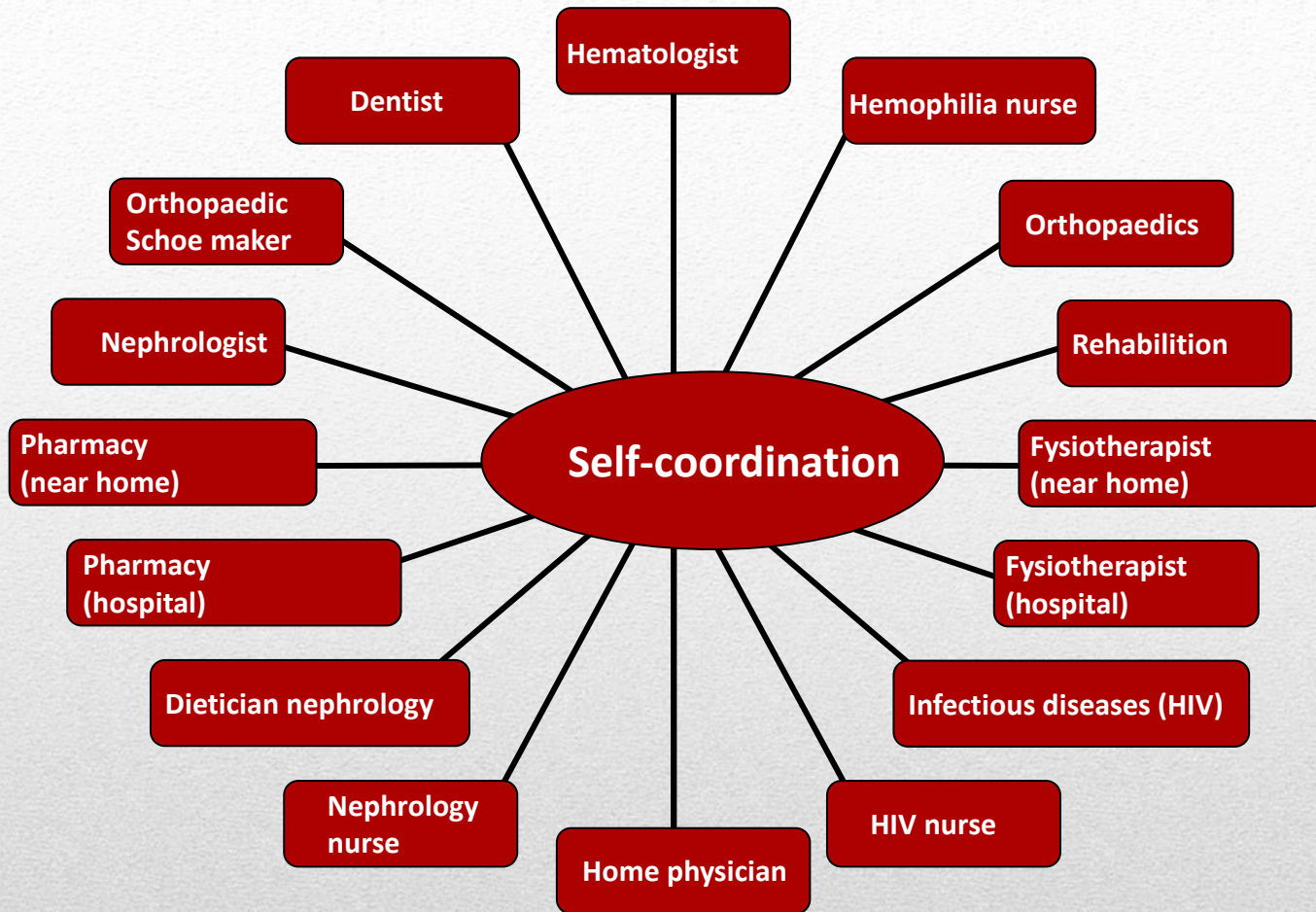
HCV (2015)

Consequences: from paediatrics to care for older people

Remarkable transitions



Rollercoaster



Contact circle

Bad joints and muscles

Stiffness, especially getting out of bed or standing up after a period of long rest

Limited walking possibilities, shopping

Tiredness because of viral infections/renal problems

Limited labour possibilities or social activities

Comorbidity as a consequence of ageing

What if your partner becomes ill?

Hemophilia & getting older



Nevertheless

Three problems:

Comorbidity & the use of multiple medications
(**polypharmacy**)

Lack of coordination between physicians and
paramedics, which requires self-coordination

Who can and is willing to take over your self-
management when you aren't able to perform that
yourself?

And who recognizes this timely?

The 'fear' factor

Hemophiliacenter/ HIV center/Nephrology center

Home physician

Other medical specialist/nurse practitioner/geriatrics

Nurse coordinator for the elderly/nursing home

Extension of own social network

Who is coordinating

You are on waiting lists like anyone else, but at more cost (loss of strength while on a waiting list)

Your rehabilitation is different from healthy elderly
And even managing daily life is different (partner ill)

The trend towards self-management should be combined with regular physio assessments & training stays providing a mental & physical boost

(Swedish Hemophilia Society: Tenerife/Gran Canaria)
Cerebral Palsy Denmark focused rehab & Agrenska (SW)



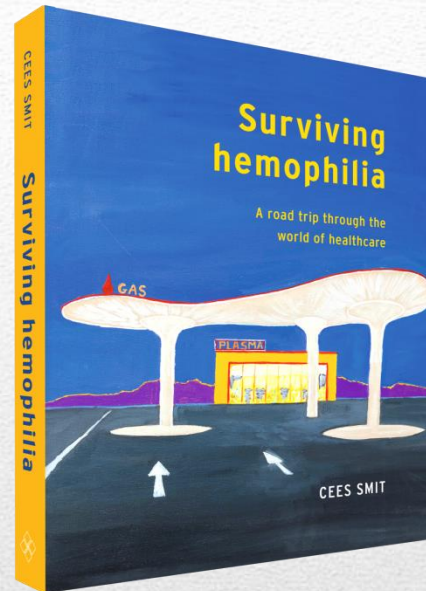
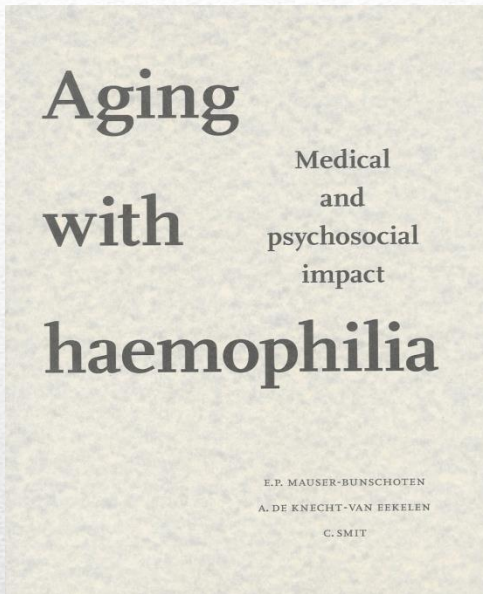
Ageing needs a new care vision

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**The need for coordination & vision
(integrated care)**

Key messages



For more information
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