

*the art of* **Ageing**  
*with comorbidities*

A personal perspective

Dr. h.c. Cees Smit  
Rotterdam, October 4, 2016

# *Messages*

**A long personal history behind each patient**

**Aging, comorbidities & the 'fear factor'**

**The need for coordination**

***At long personal history behind each patient***

# **‘Journey’, 1975**

*‘The disease we have fought is hemophilia. Every family with a handicapped or chronically ill child shares the same problems: lack of money, isolation from the community of the healthy, prejudice, misunderstanding in schools, loneliness, boredom, depression’*

*(ref. Robert & Suzanne Massie, Journey, 1975, p. XI)*

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

## CORNELIS

M. SMIT-KROON  
J. SMIT  
en WILLY



Wij noemen hem KEES

Nieuwe Niedorp,  
1 Januari 1951  
Laagzijde B 249

# Hemophilia: my own patient journey

Hemophilia, a rare disease

1 :10.000 (the Netherlands  $\approx$  1.700 patients)

Mostly males, females carriers

X-linked recessive disorder

Hemophilia A, factor VIII

Hemophilia B, factor IX

Severe, moderate and mild

Characterized by mostly spontaneous internal bleeds in muscles and joints

Furthermore through trauma, accidents and operations

No treatment possibilities before 1965





Janie Kuiper  
79









# **D.E.S.**

## **The Bitter Pill**

How Medical  
Indifference Turned  
a "Miracle" Drug  
Into a  
National  
Nightmare



**ROBERT MEYERS**





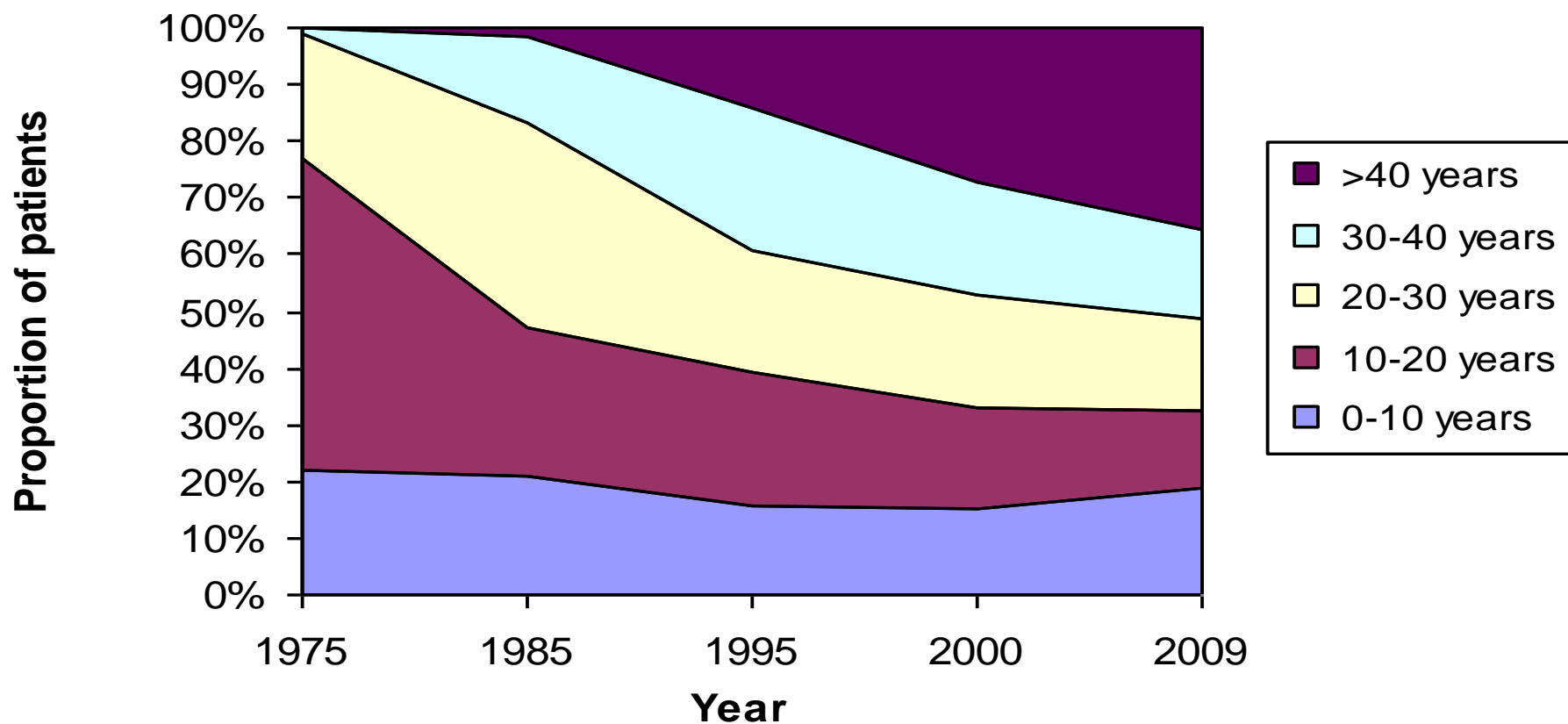








# Aging in severe hemophilia (n=338)



*The success story of  
pediatric medicine:*

*Young children become  
older and older*





**HIV**

**HCV**

# **‘A song in the night’, 2012**

*‘My hemophilia, the one thing that I had thought would define my life from birth to death, had been utterly, totally and permanently cured’*

*(ref. A Song in the night, a memoir of resilience’, Robert IV Massie, 2012, p. 269)*



# Remarkable transitions

**From unmet medical need → good treatment**

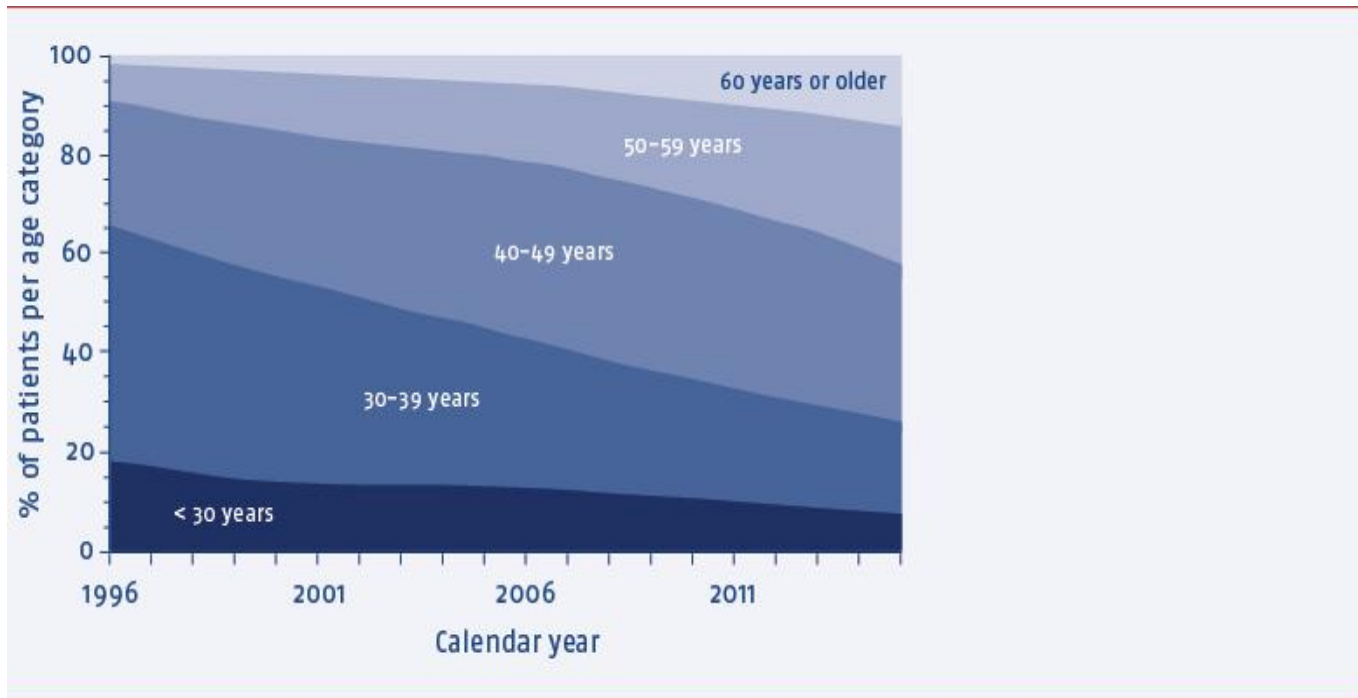
**Hemophilia (in the seventies)**

**HIV (in the nineties)**

**HCV (in the 2015's)**

**Consequences: transition to care for older people**

# Aging in hiv/aids



(ref. van Sighem A.I., Gras L., Smit C., Stolte I., Reiss P. Monitoring Report 2015. Human Immunodeficiency Virus (HIV) Infection in the Netherlands. Amsterdam: Stichting HIV Monitoring, 2015. Reproduced with permission).

*Aging, comorbidities  
& the 'fear factor'*

# Problems in elderly hemophiliacs

## Bad joints and muscles

Stiffness, especially upon waking or after sitting for a long period of time

Limited walking, shopping

Tiredness because of viral infections

Limited ability to work / retirement

Comorbidity due to older age

Aging  
with  
haemophilia


Medical  
and  
psychosocial  
impact

E.P. MAUSER-BUNSCHOTEN

A. DE KNECHT-VAN EEKELEN

C. SMIT







# Aging with HIV/AIDS in the Netherlands

A limited number of USB-sticks with the pdf  
of this publication is distributed from  
the Aids Fonds and the EACS booths  
at the XVIII International AIDS  
Conference - Vienna - July 18-23, 2010

**Dutch Booth and EACS Booth in the Exhibition Hall**

The production of Aging with HIV/AIDS in the Netherlands was  
supported through joint funding by both the Aids Fonds and  
the European AIDS Clinical Society (EACS).

100-01 Aging with HIV/AIDS

100-01 Aging with HIV/AIDS

# Aging with HIV/AIDS

There is no effective link  
between treatment  
and care and  
between welfare  
and support for the  
elderly person with HIV

# in the Netherlands



# Really Getting Older & The Issue of Comorbidity (1)

## Functional limitations

*Physical deterioration, fatigue*

*Less ability for self-care*

## Psychological complaints/symptoms

*Fear and depression*

*Feeling of losing control*

# Really Getting Older & the Issue of Comorbidity (2)

## Social problems

*Lack of understanding*

*Decrease of social contacts*

## Societal problems

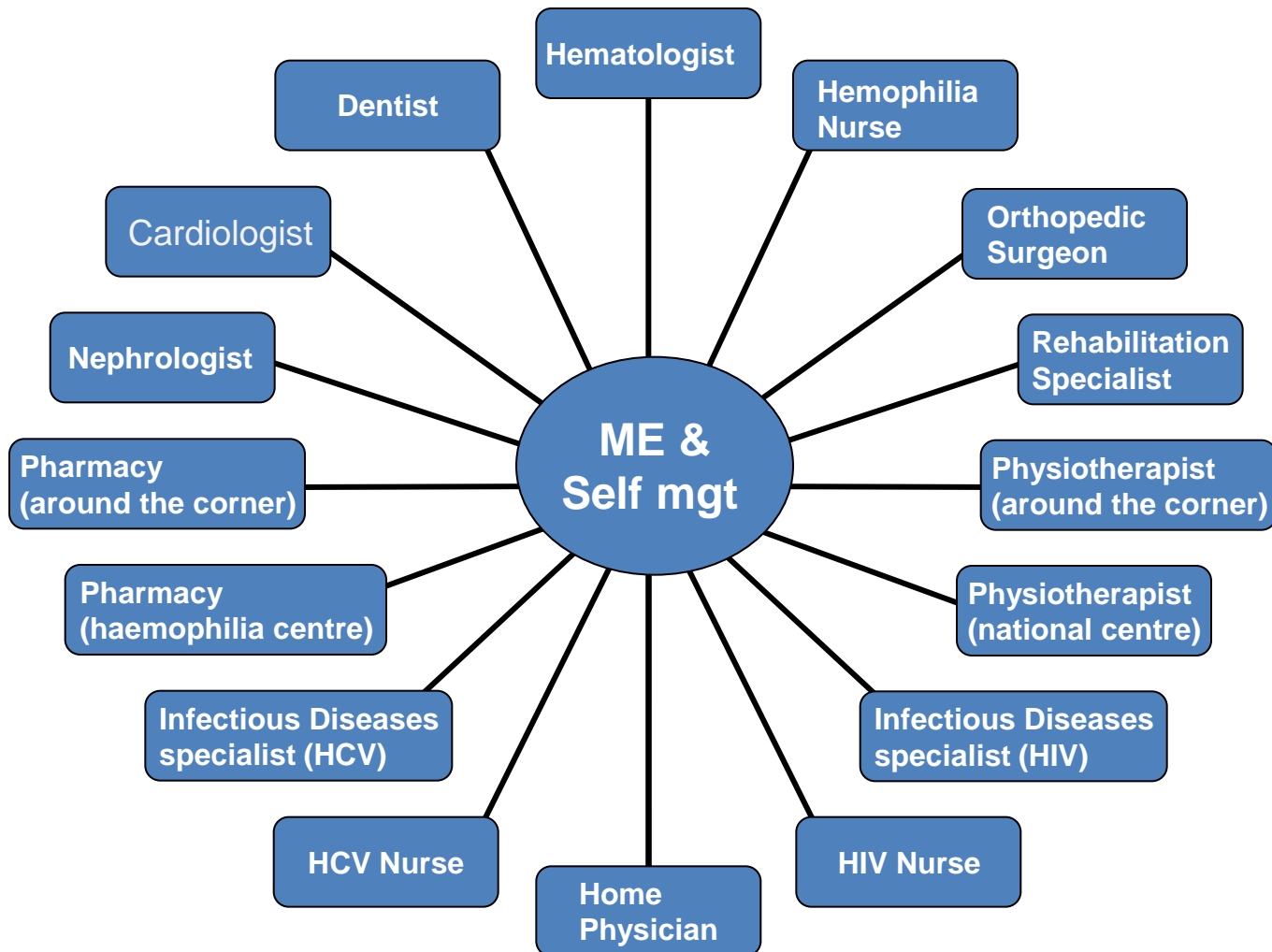
*Less participation in labour and leisure  
time activities*

*An increase of disease costs*

# Really Getting Older & the Issue of Comorbidity (3)

- But **the other side of the coin: coping skills !**
- ‘With regard to ageing: ..... ‘
- ‘In jest, I tell people that I am holding my own while brothers and other relatives are going downhill as they hit their sixties. I am hoping to be completely caught up to them by age 70. And my coping skills are better than theirs!’

# A Circle Full of Health Care Contacts





# The 'fear factor'

Three problems:

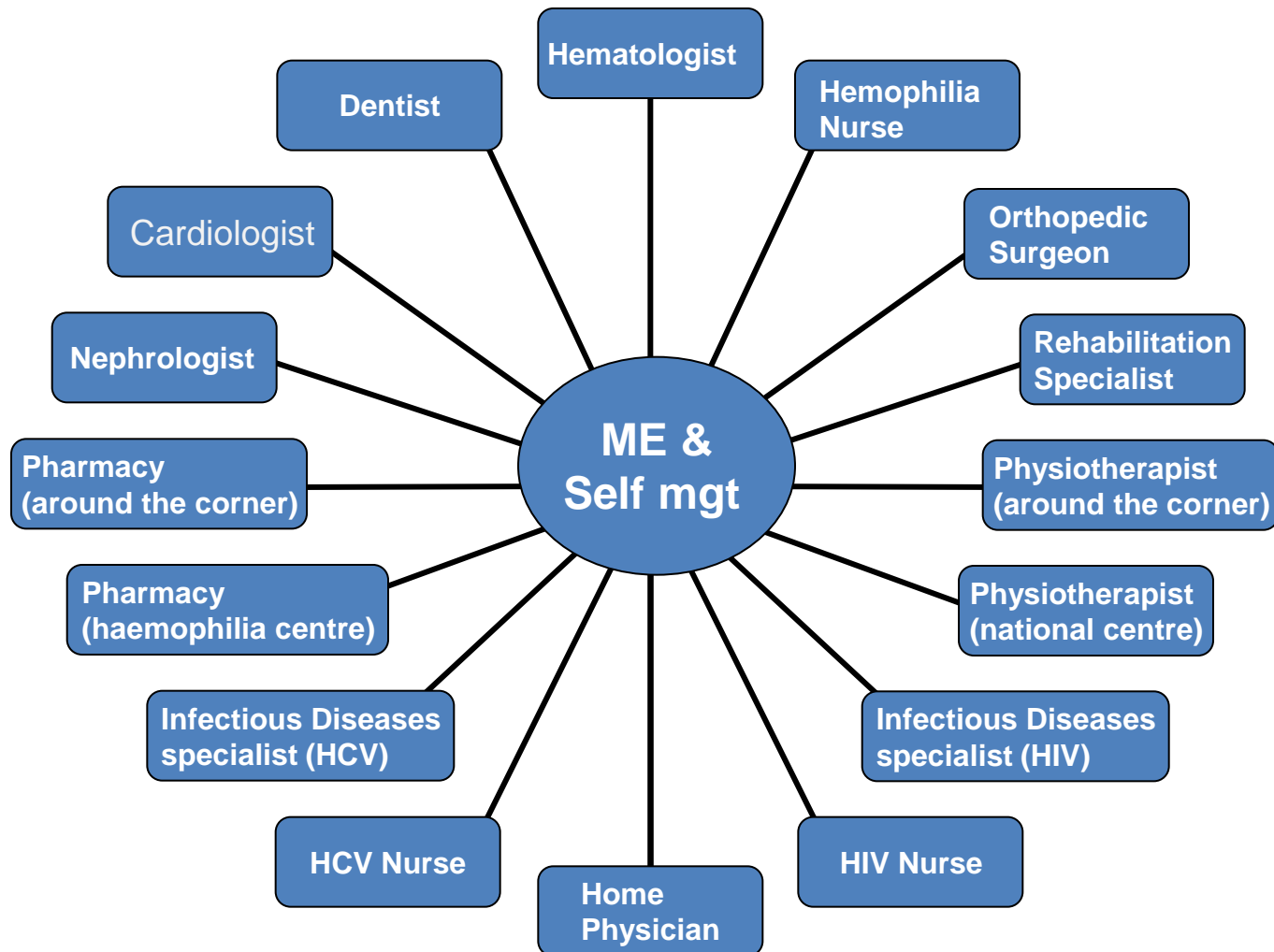
Comorbidity & the use of multiple medication  
(polypharmacy)

Lack of coordination between physicians and other staff,  
which needs self-coordination

Who can and lead coordination when self-care  
is no longer possible ?

*The need for coordination*

# A Circle Full of Health Care Contacts

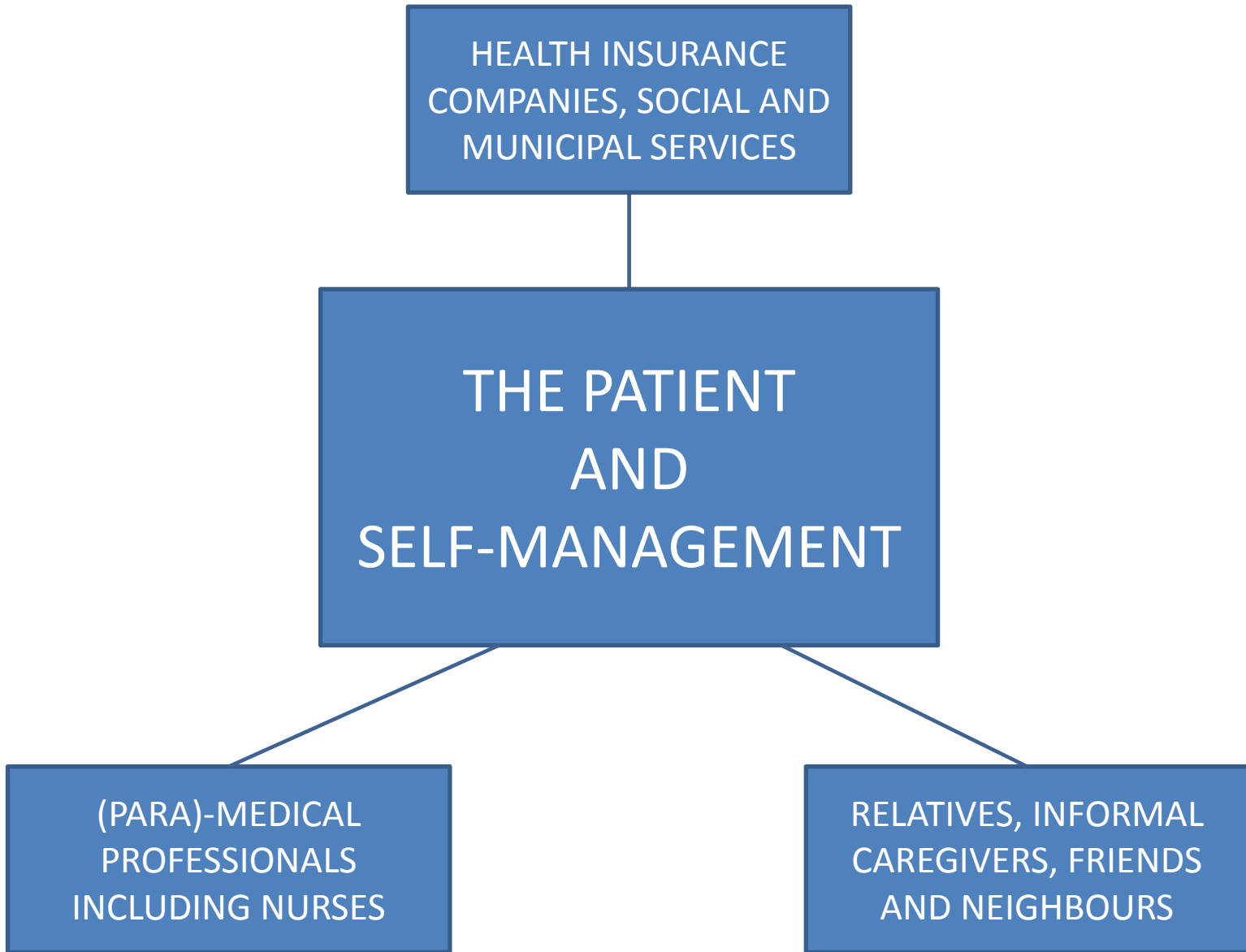


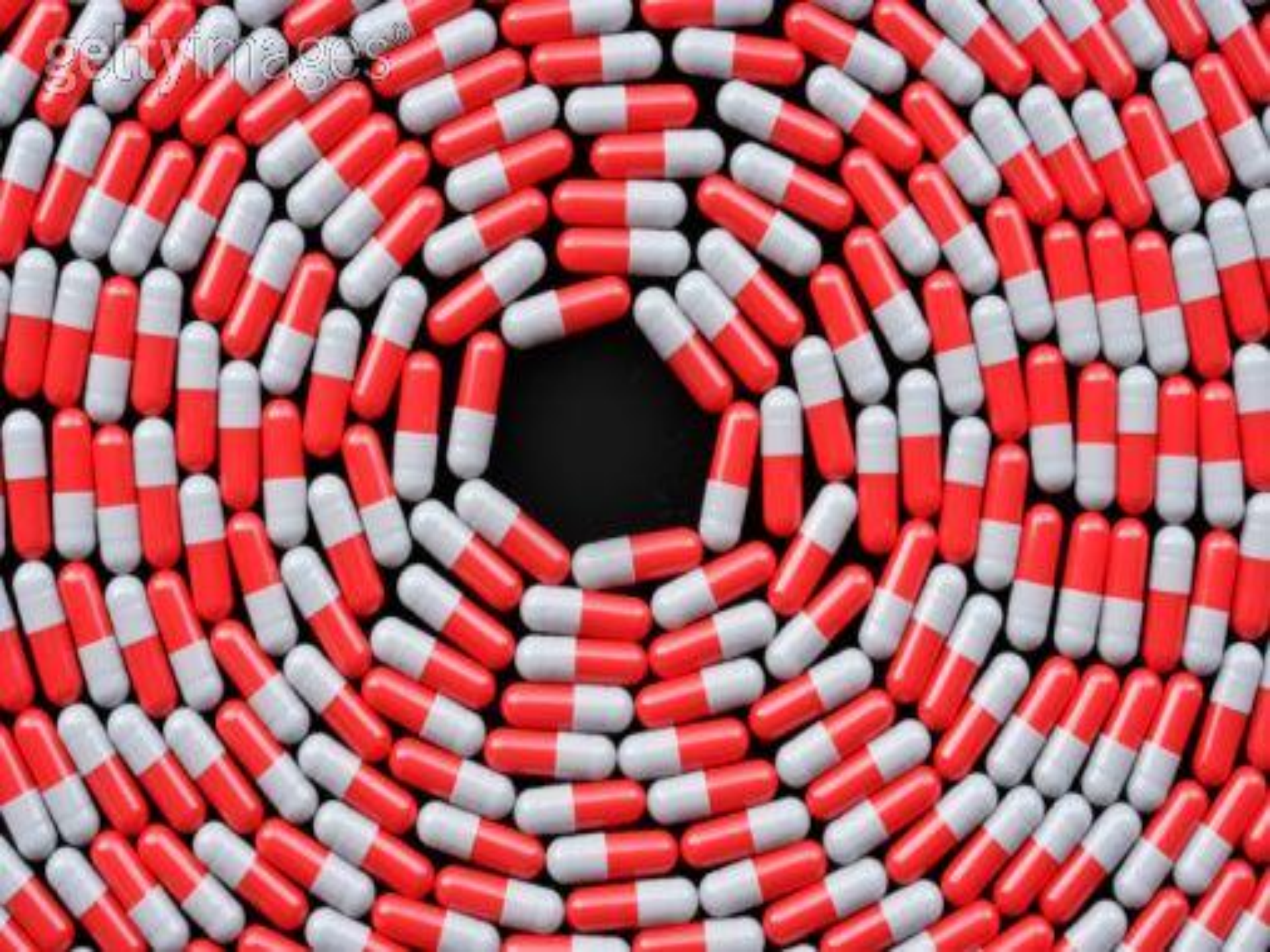
HEALTH INSURANCE  
COMPANIES, SOCIAL AND  
MUNICIPAL SERVICES

THE PATIENT  
AND  
SELF-MANAGEMENT

(PARA)-MEDICAL  
PROFESSIONALS  
INCLUDING NURSES

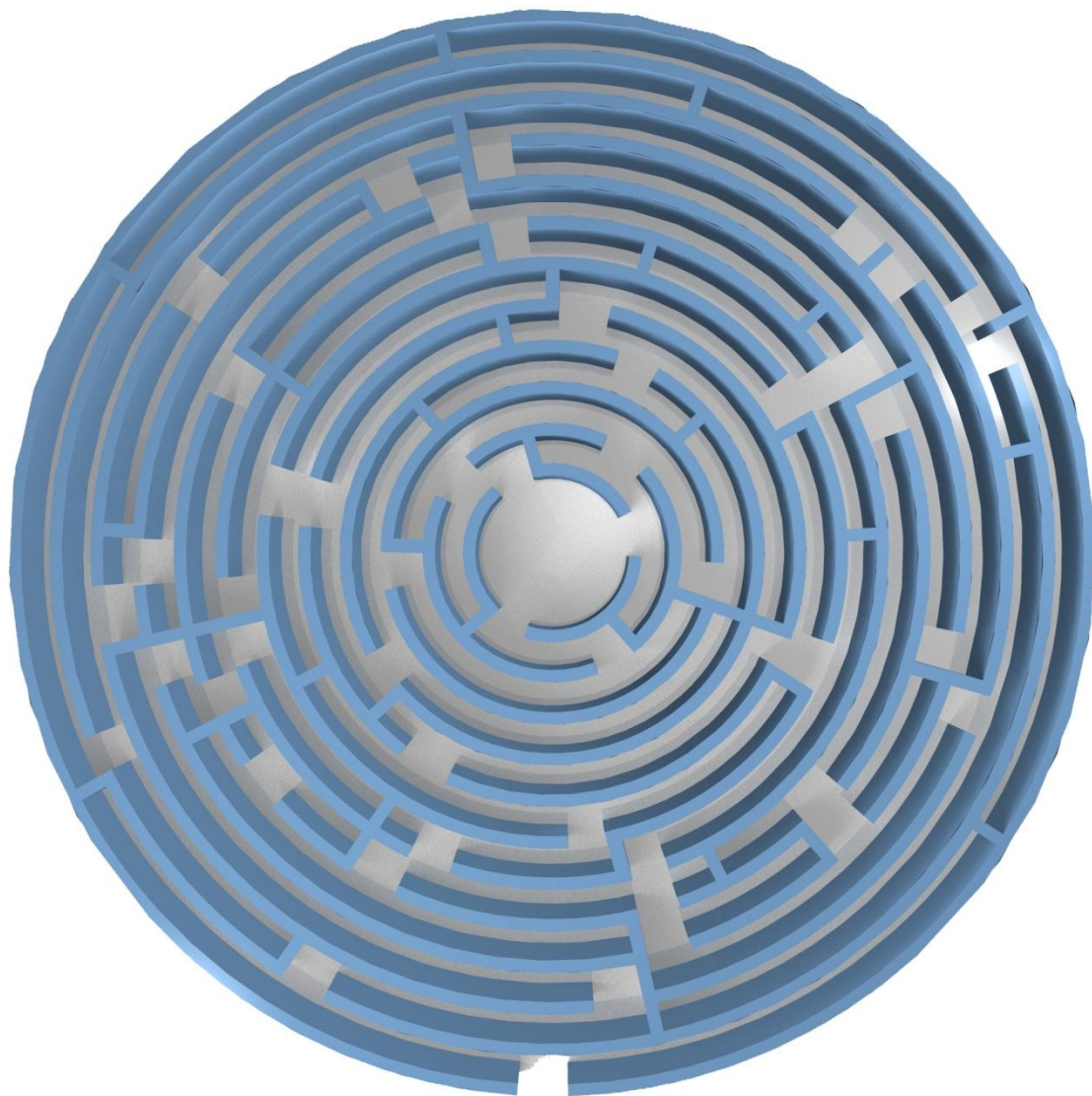
RELATIVES, INFORMAL  
CAREGIVERS, FRIENDS  
AND NEIGHBOURS













# Who should or could coordinate ?

- Hemophilia centre / HIV centre
- Home physician
- Other medical specialists / nurses
- Nurse coordinator for the elderly, nursing homes
- Extension of my own network



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# Patient and public involvement in future care for senior citizens





# The Wheel of Life

A Memoir of Living and Dying



"An inspiring account of exploration,  
conviction, and service. . . . This book chronicles a life  
lived passionately, compassionately, and well."

—Richard Hoffman, *New Age Journal*

Elisabeth  
Kübler-Ross, M.D.

Author of *On Death and Dying*