



21ST AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD AND
RARE BLEEDING DISORDERS
WORKING TOGETHER - IMPROVING OUTCOMES

Getting Older Medical Issues

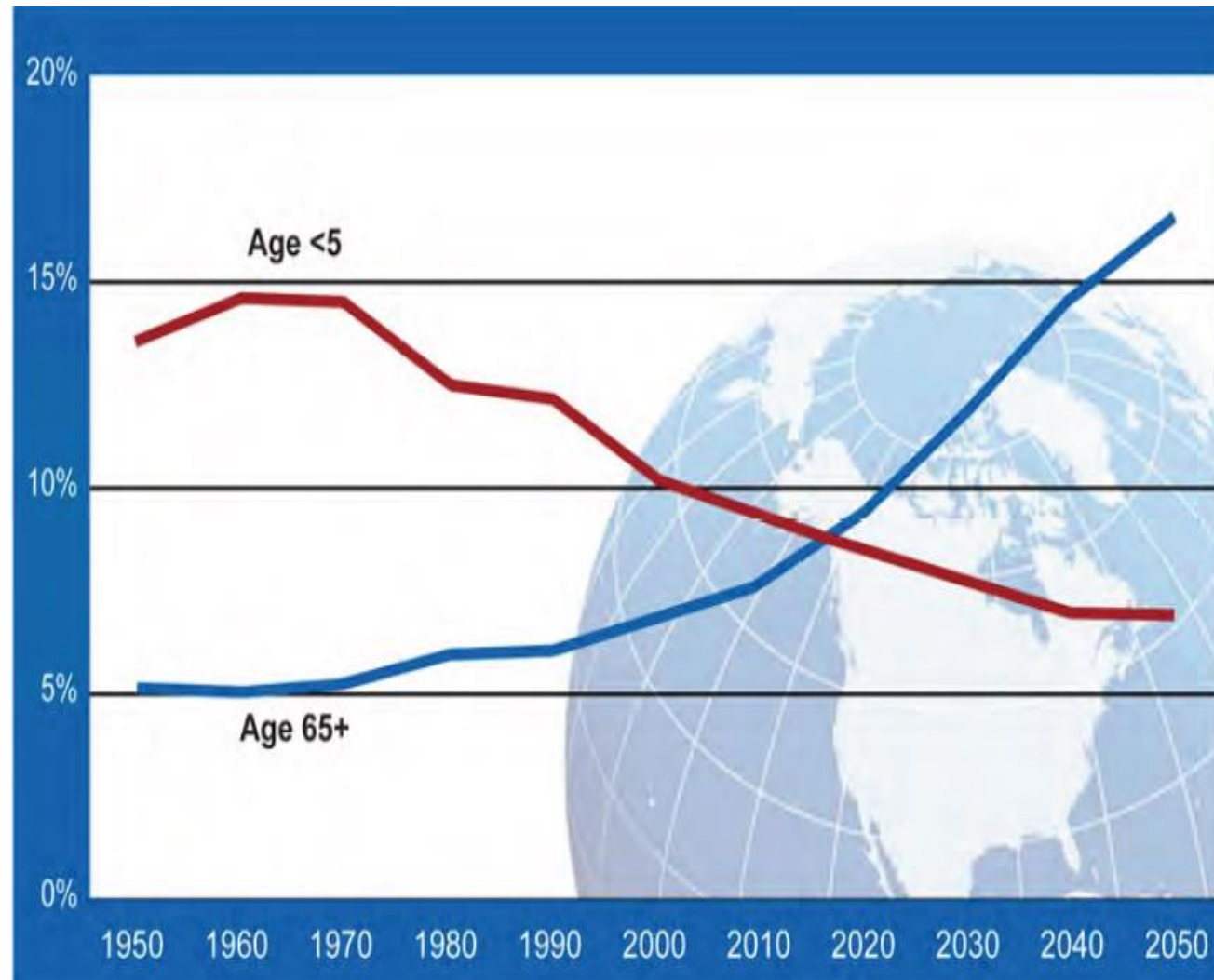
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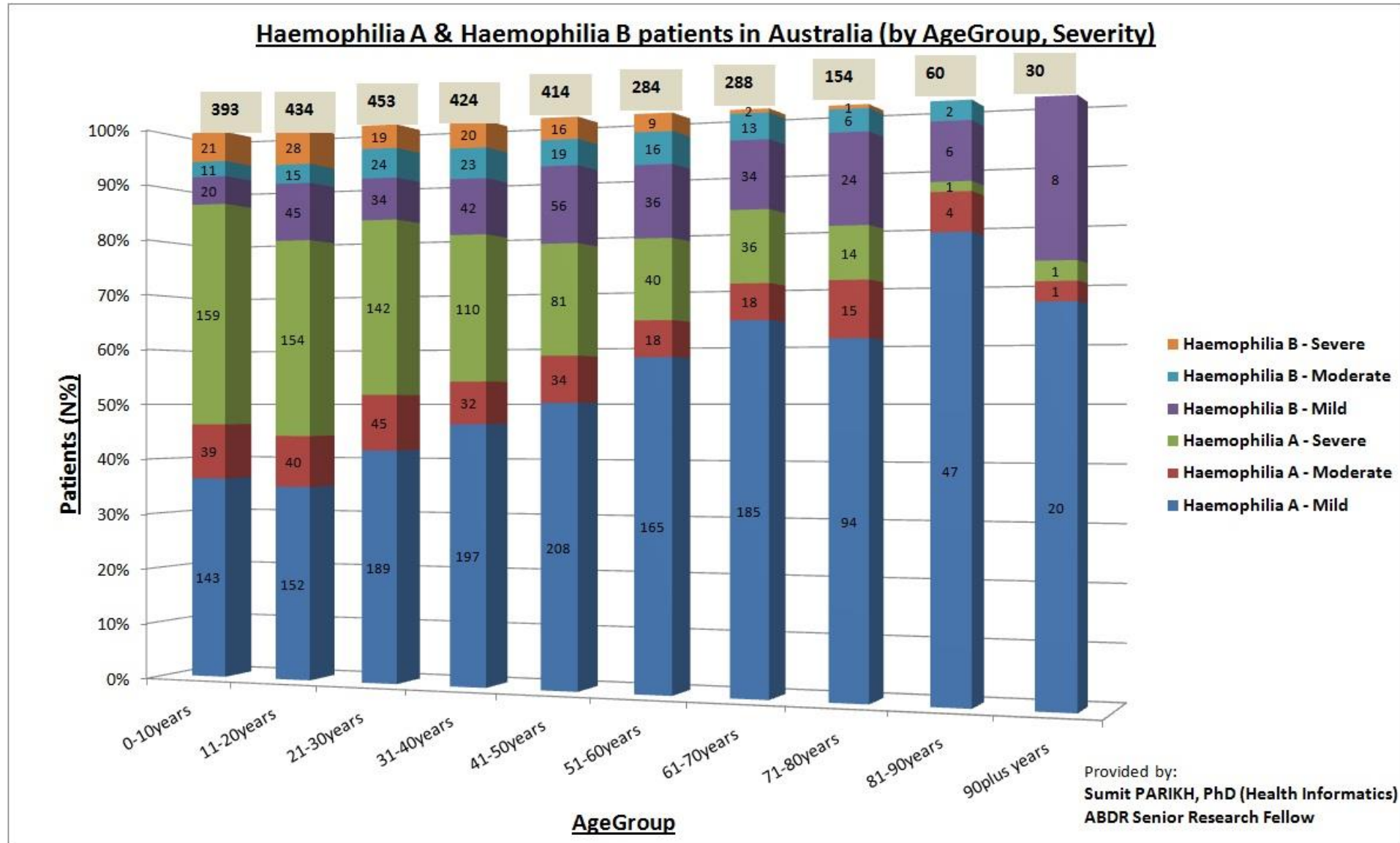
<https://www.who.int/news-room/fact-sheets/detail/ageing-and-health>

- By 2050, around one quarter of all Australians will be aged 65 years and over, with the proportion of younger Australians declining
- By 2050, the world's population aged 60 years and older is expected to total 2 billion
- All countries face major challenges to ensure that their health and social systems are ready to make the most of this demographic shift.
- A longer life brings with it opportunities, not only for older people and their families, but also for societies as a whole.
- There is no “typical” older person.

Young people and older people as percentage of the population: 1950–2050



Age distribution of patients with Haemophilia in Australia (2019)





Ageing and Haemophilia

Advances in the development of effective and safer treatments for haemophilia over the last 50 years have resulted in a significant increase in the life expectancy of persons with haemophilia and other bleeding disorders

Life expectancy for persons with haemophilia has increased significantly from 11.4 years in 1920 to a potentially normal life span today^{1,2}

As life spans normalize with adequate haemophilia care, people with inherited bleeding disorders are now transitioning from a focus primarily on bleeding and its complications to a focus that includes health promotion and disease prevention.



Getting older with a bleeding disorder

Needs assessment report

May 2020



Navigating Time and Space: Experiences of Aging with Hemophilia

NHF FINAL REPORT | INNOVATIVE INVESTIGATOR AWARD

SUPPORTED BY



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

5.4.1 ABOUT THE OLDER PERSON WITH A BLEEDING DISORDER

Table 7: Aspirations and goals of the older person with a bleeding disorder

Older people with bleeding disorders responses	Partner/family responses
<ul style="list-style-type: none">• Good health and quality of life• Retaining mobility and independence• Able to pursue personal interests• Travel• Spending time with friends and family• Retiring; or continuing to work, but reduced hours• Contributing to society	<ul style="list-style-type: none">• Good health and quality of life• Access to appropriate treatment and care• Travel• Financial security• Staying active and independent• Using their talents and skills• Enjoying their interests

Challenges and concerns for the older person with a bleeding disorder

What will help the older person with a bleeding disorder

Challenges and concerns of partners/carers

Navigating Time and Space: Experiences of Aging with Hemophilia

- **80% of older participants report that their *unexpected longevity has affected them in profound ways***
 - *advocacy for medical coverage*
 - *education for medical providers to understand the unique needs of older patients with haemophilila*
 - *unexpected longevity has led to *caregiving roles* and *concern about care* (e.g., [Who will care for me?](#)) in older adulthood.*

As the interviews probed a lifetime of experience, the participants noted *complex trauma histories* related to social exclusion, stigma, and bullying/cruelty and an interweaving of physical and emotional pain.

Medical Issues with Aging and Haemophilia

Cardiovascular Disease

- Hypertension, Obesity, Diabetes

Falls Risk

- Mobility
 - Arthritis : haemophilic arthropathy, osteoarthritis
- Osteoporosis

Decrease Visual Acuity

Dementia

Malignancy

Depression

Non-haemophilia related hospital admissions

Care outside the home/ Ageing Carers

Up-skilling and engaging other medical and allied health specialists to be part of the HTC community

Partnering with General Practitioners

HTC dealing with these medical issues

Ageing, Health Risks and Other co-morbidities :

Cardiovascular Disease

Cardiovascular disease (CVD) management is challenging, having to manage anticoagulants; anti-platelet agents and cardiac surgery – all associated with increase bleeding risk.

Encouraging risk reduction and optimising other factors

- Smoking cessation
- Hypertension management
- Hyperlipidaemia management
- Type 2 diabetes management
- Overweight/Obesity management

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**"High blood pressure, high cholesterol, high blood sugar,
high anxiety...getting high is no fun at my age!"**

Ageing, Health Risks and Other co-morbidities: **Overweight/Obesity**



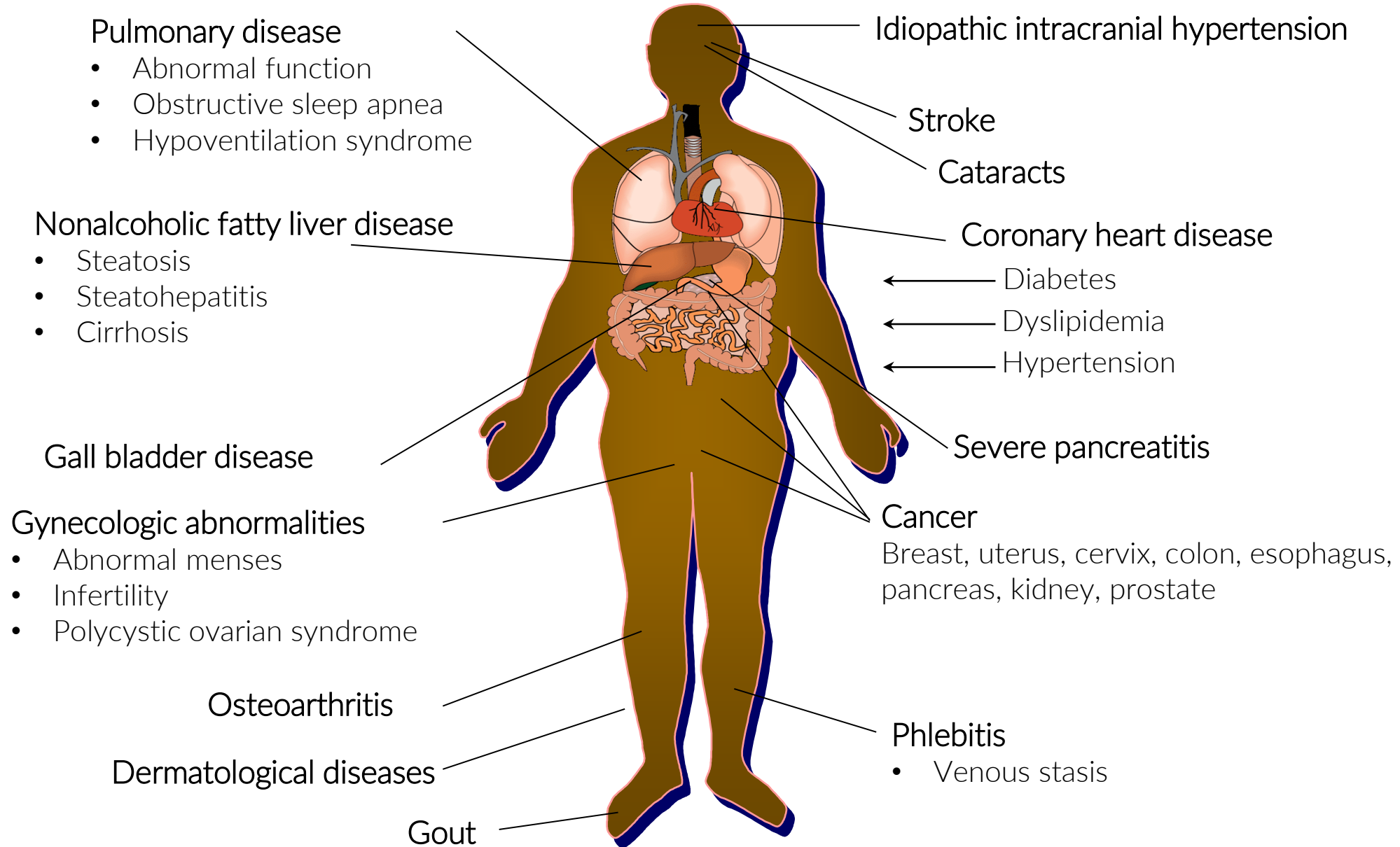
Body mass index (BMI) between 25 and 29.9 are overweight, and those with a BMI of 30 and above are obese.

Obesity in persons with haemophilia contributes negatively to joint health with increase bleeds and immobility and and impaired healing after orthopaedic surgery.

Exercise is beneficial : promotes health joints, muscle tone, optimal body weight, bone density and quality of life.
(and can be challenging)



Medical complications of obesity



Ageing, Health Risks and Other co-morbidities : Musculoskeletal Issues

- Chronic haemophilic arthropathy.
- Reduced bone mineral density (BMD), 2/3 of patients with moderate or severe haemophilia older than 50 years having osteoporosis
- Risk of falls/fractures and other injuries



Multi-disciplinary approach : Assessment for sensory changes, balance, mobility changes, and circulatory impairment will lead to practical recommendations.

Orthopaedic issues

For adults with existing arthropathy:

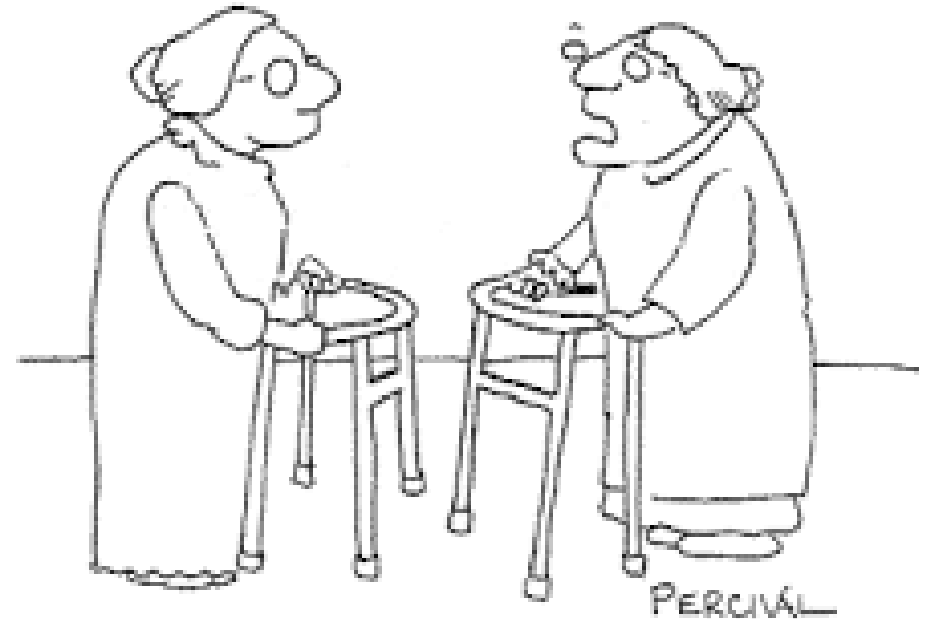
- Haemophilic arthropathy may be complicated by degenerative joint disease
- Survival of joint prostheses
- Adults with existing prostheses requiring revision
- By 2030, in the general population:
 - 1st total knee replacements will increase by 673%
 - 1st total hip replacements will increase by 174%

Holistic approach to maintaining good joint health

- 'Not all about factor concentrate'
- Early in life –establish good patterns of **health**, exercise and nutrition.
- Build a healthier population of patients with haemophilia

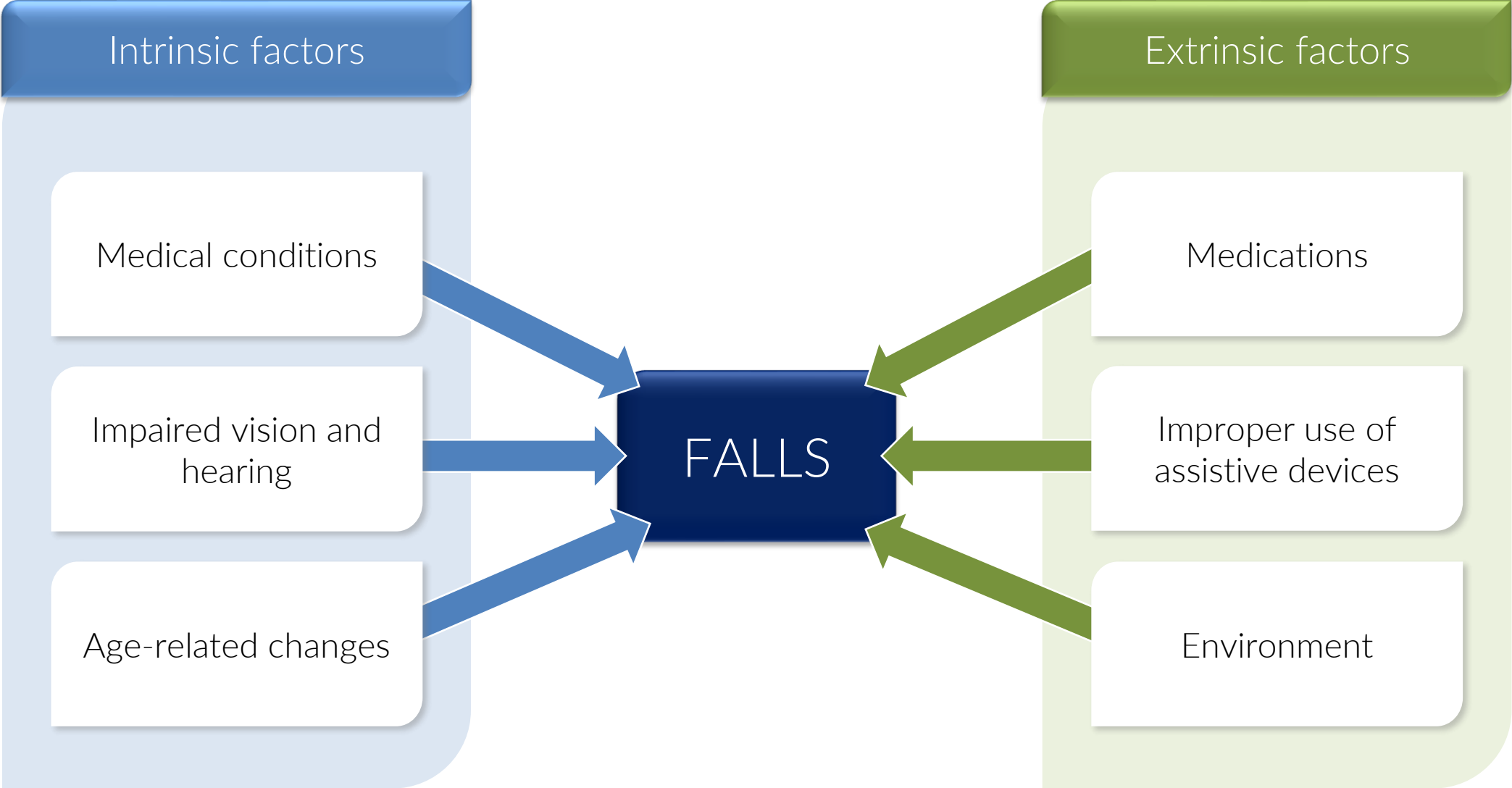
Falls: prevalence

- 30% of those aged over 65 years fall annually
- Half are repeat fallers
- Falls go up with each decade of life
- Over half of those in nursing homes and hospitals will fall each year



"The trouble with today's generation is that they can't stand on their own two feet."

Falls are multifactorial



Normal changes with ageing

- Neurologic
 - Increased reaction time
 - Decreased righting reflexes
 - Decreased proprioception
- Vision changes
 - Decreased accommodation and dark adaptation
- Decreased muscle mass
- Gait Changes
 - Slower gait
 - Decreased stride length and arm swing
 - Forward flexion at head and torso
 - Increased flexion at shoulders and knees
 - Increased lateral sway



Ageing, Health Risks and Other co-morbidities : **Cancer**

Risk of malignancy in patients with bleeding disorders is similar to the general population

- except HCV associated liver cancer; and HIV related malignancy

Factor replacement for invasive investigations : biopsy and surgery

- planning and coordination with HTC

Chemotherapy should not be withheld; and factor replacement may be necessary if blood counts (platelets) drop; increased bleeding with some chemotherapy agents

- May need to start prophylaxis/IV access issues

Issues for haemophilia centres

Clinical care has been dominated by:

1. Risk of bleeding
2. Joint disease
3. Transfusion-transmitted infection

Models of comprehensive care adapted to deal with these issues

Much of the general medical care for patients delivered or coordinated through haemophilia centres

How do we adapt to deal with medical challenges of older age?

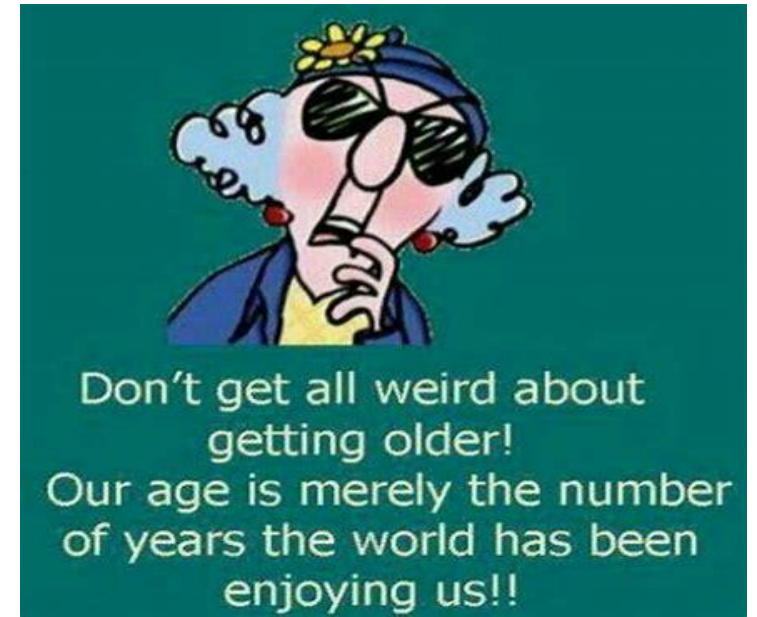
Aging gracefully is an art. Aging disgracefully is an absolute blast!



Summary:

As life spans normalize with adequate treatment

- care not only focusing on bleed prevention and management
- focus that includes health promotion and disease prevention



- Good collaboration with general practitioners, other specialists and HTC is important
- Models of care need to focus on the ongoing needs of our patients
- Need adequate and equitable health and social systems