

Ageing with a bleeding disorder

Mapping the needs of patients
aged 50+ across the EHC membership

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Why are we here?

- Increase in the life expectancy, general population & bleeding disorders: **this is the first generation ageing with a bleeding disorder!**
- Increase in the quality of life: **50 is the new 30!**

BUT for the rare diseases **Life expectancy = ~~Quality~~ of Life**

What do we expect for healthy ageing with a bleeding disorder?

- Quality of life
- Independence
- Integrity of care

EHC Needs Assessment Survey

#ageinghealthy

On a Pathway Towards Healthy Ageing: **Possibilities for Support**

Thanks to the improvements in treatment today people with haemophilia and other rare bleeding disorders are living longer than ever. However, there are still challenges that need to be addressed. To understand what those challenges are and how to best address them, the EHC carried out a needs assessment survey* among the members of the bleeding disorders community.



* Survey was carried out in quarter 3 of 2021, **181** valid responses from **13** countries were received, representing men and women with a variety of bleeding disorders in the age range of **50-81** years.



"I still **work**, pay my mortgage and enjoy nice dates with my wife!"



"I am a volunteer and work with immigrants. I **play piano** for people in nursing homes. I have a coffee in a shopping centre every day. I like cooking!"



"I go to **aqua-gym** every week and play tennis with a friend regularly."

"I join almost every event my NMO organises."





"We are physically and socially active people with a bleeding disorder and generally do not face many challenges that we find worrisome. However, difficult medical management of the bleeding disorder, e.g. venous access, joint rigidity, adverse events etc., as well as access to relevant multidisciplinary care specialists can be challenging. As we go through the ageing process, the adaptation of the treatment regimen to our age and current lifestyle is important, as well as keeping an eye on the bleeding disorder related co-morbidities."





How to support ?

- ▶ Information regarding complexity of ageing with a bleeding disorder.
- ▶ Expert advice on strategies for improved quality of life, e.g. pain management, nutrition, sports and physiotherapy.
- ▶ Information regarding management of co-morbidities and management of a variety of medications and interventions.
- ▶ Access to the relevant multidisciplinary care specialists.
- ▶ Advocacy strategies to help improve the situation of ageing patients with bleeding disorders.



Some concrete ideas

-  Online peer support groups
-  Advice on how to make home/ car adaptations
-  Advice for moving into senior home
-  Advice on how to manage a household with increasing mobility challenges
-  Pain management

- ▶ **Support and advice in management of every-day activities, e.g. pursuing hobby, participating in household activities etc.**
- ▶ **Provide information on financial planning/financial advice.**
- ▶ **Access to professional psychological support.**
- ▶ **Sharing experiences and stories of peers.**



IT education and training so that the seniors can join online events



Online legal support



Support with insurance



Home delivery of treatment...

Where do we go with this information?

<p>Known knowns – the facts that we face...</p> <ul style="list-style-type: none">- Treatment and care needs- Non-medical needs identified by the patient community- Disparity of care on European level	<p>Known Unknowns – unmet systemic needs...</p> <ul style="list-style-type: none">- Total care concept- Coordination of care- Aligned care systems across Europe- HCP education on rare diseases
<p>Unknown knowns – what solutions may be already there?</p> <ul style="list-style-type: none">- Paedatric approach- Care in the community- Intersectoral & intergenerational approach	<p>Unknown unknowns</p> <ul style="list-style-type: none">- Long-term effect of new drugs- Impact of polypharmacy- Disease-based co-morbidity drug research

What is the picture in your context?

<p>Known knowns – the facts that we face...</p>	<p>Known Unknowns – unmet systemic needs...</p>
<p>Unknown knowns – what solutions may be already there?</p>	<p>Unknown unknowns</p>

Thank you!