



# ARE YOU IN?

A handbook for better inclusion of people with inhibitors  
in the life of the National Member Organisation





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# ACKNOWLEDGEMENTS

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## **European Inhibitor Network of EHC - [inhibitor.ehc.eu](http://inhibitor.ehc.eu)**

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# INTRODUCTION

The **European Inhibitor Network** (EIN) was launched by the European Haemophilia Consortium (EHC) in 2016 and since the beginning it was clear that a tool will have to be created for the National Member Organisations (NMOs) to support them in their efforts to include people with bleeding disorders who are affected by inhibitors in the life of the NMO.

In 2016 three surveys were carried out to help shape the work of the EIN - for healthcare professionals, individuals and NMOs. The two latter ones informed the EHC Inhibitor working group about the needs of people who are affected by inhibitors, as well as about the availability of specialised materials and services available for them on the level of the NMOs.

Having in mind the small number of people with inhibitors (PWI) nationally, there were only a few NMOs that had resources, activities and materials dedicated to PWI, while the information gained from individuals themselves showed that there is a great need for these things and for PWI to be put in the focus of the NMO.

The best approach to put those who are affected by inhibitors in focus is to develop practices of inclusion in a way that PWIs are the ones who can be a part of decision-making about issues related to them. This way PWI, their caregivers and families will be able to take ownership to ensure that their needs are being met by the NMO.

The **aim of this handbook** is to assist NMOs in enabling PWI to become educated about their condition, empowered and actively engaged in their NMO and their self-advocacy. This material contains information, resources, ideas and methods to help.

Brief information about inhibitors and inhibitor management will provide the NMOs with ready-made material to pass on to PWI and their caregivers; the chapter on 'Who are the people affected by inhibitors?' will help NMOs to identify who are the people that need their support and also give some ideas on how to do that. This handbook also contains a chapter on 'Useful methodologies' that can be used by the NMOs when they are organising an event for PWI, caregivers and families, as well as one that outlines the ways to include PWI in the structures of the NMO, so that they can grow from being recipients of support to active participants in providing support to others.

We hope that this material will be useful for the NMOs and will result in better inclusion of people with inhibitors in the life of NMOs!

Sincerely yours,  
EHC Inhibitor Working Group

# KEY TERMS

These are the key terms used in handbook.

**Anamnestic response** - renewed rapid production of an antibody (inhibitor) on the second (or subsequent) encounter with the same antigen (external coagulation factor VIII or IX in case of haemophilia).

**Bethesda Unit (BU)** - measure of inhibitor activity: the amount of inhibitor that will inactivate 50% of 0.5 unit of a coagulation factor during the incubation period. BU is named after Bethesda assay- a test used to measure inhibitors.

**ED** - exposure days. The number of days when factor treatment was received. For example, if somebody was diagnosed with haemophilia four weeks ago, but has received treatment prophylactically two times per week, the count of EDs would be 8.

**HTC** - haemophilia treatment centre. A general term to refer to the haemophilia treatment centres. HTCs can be also certified as European Haemophilia Treatment Centres (EHTC) and European Haemophilia Comprehensive Care Centres (EHCCC). The latter would most likely have good multidisciplinary facilities.

**Incidence** - relates to the number of patients who develop an inhibitor.

**ITI** - immune tolerance induction. With ITI therapy, factor concentrate is given regularly over a period of time until the body suppresses the immune reaction and the antibody disappears.

**Nijmegen modification** - a modification to the Bethesda assay that provides improved specificity and reliability.

**NMO** - National Member Organisation.

**Prevalence** - indicates the proportion of affected patients at a specific time point.

**PUP** - previously untreated patient. A person with haemophilia or other bleeding disorder that has not received treatment with factor replacement products. In case of severe haemophilia this would mean that PUP is a child of less than two years of age.

**PTP** - previously treated patient. A person with haemophilia or other bleeding disorder that already has received treatment with factor replacement products.

**PWI** - person with inhibitors.

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# CHAPTER 1



## BACKGROUND INFORMATION ABOUT INHIBITORS



## WHAT ARE INHIBITORS?

Inhibitors in haemophilia are antibodies that develop as a reaction of the body to infused coagulation factor VIII or IX. The immune system sees the external factor as a foreign protein, which is a normal way for the body to detect and neutralise potential threats, e.g. pathogens. When the infused coagulation factor becomes the target of this response, it is eliminated and thus, the replacement therapy stops working.

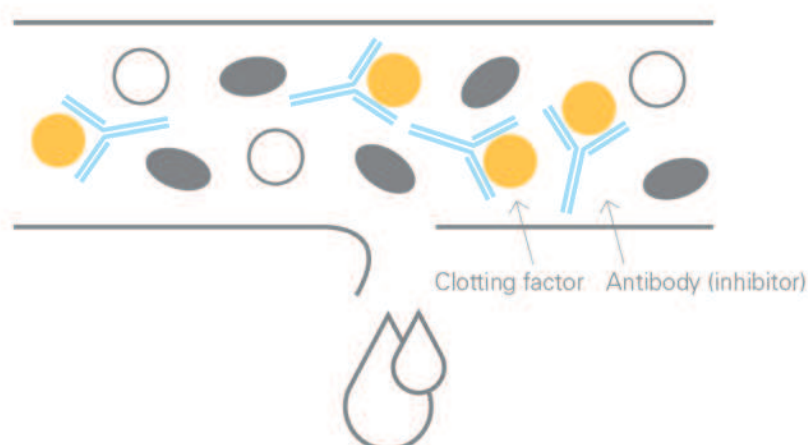
Currently, when the risk of transmission of blood borne pathogens such as HIV or hepatitis C is effectively eliminated, inhibitor development is the most serious complication in haemophilia.

Approximately 30% of patients with severe haemophilia A develop inhibitors, but significantly less patients with non-severe haemophilia A (around 3–13%). The incidence of inhibitor development among patients with haemophilia B is much lower than in haemophilia A, in the range of 1–6%.

In many patients inhibitors disappear spontaneously (they are called transient inhibitors) or are eliminated as a result of immune tolerance induction therapy (ITI). Therefore the reported overall prevalence of inhibitors in haemophilia is 5–7%.

Inhibitors are classified into low (<5 Bethesda Units [BU])/ml) and high (>5BU/ml) titre, and may be further classified as either low- or high-responding, according to whether the titre rises significantly after treatment with factor VIII.

In cases where a patient with non-severe haemophilia develops inhibitors against factor VIII, the body's own clotting factor may also be inactivated. This can result in the change of a previously moderate/mild disorder into a severe phenotype.



**Illustration:** Inhibitor binds to clotting factor (VIII or IX) thus preventing it from performing its functions.

## RISK FACTORS - ACROSS A LIFE-SPAN

Patients and their caregivers should be aware that inhibitors pose a life-long risk, especially to patients falling into categories that are more predisposed to inhibitor development.

There are several factors that may contribute to inhibitor development. These factors are complex and not completely understood. These factors may include the following:

- **Genetic factors** – the type of genetic mutation (e.g. large deletions and nonsense mutation) determines disease severity, and more severe disease is associated with greater inhibitor risk.
- **Family history** – a patient with a family history of inhibitor development is more likely to develop inhibitors as well.
- **Ethnic background** – according to several studies, patients with African-Caribbean and Hispanic ancestry are significantly more likely to develop inhibitors.
- **Age** – the highest risk of inhibitor development is in children under the age of five years or PUPs (Previously Untreated Patients) as the first 50 exposure days (ED) represent the high-risk period. A second but much smaller peak of inhibitor development has been observed in older patients in their 60s and beyond.
- **Treatment options** – a recent prospective randomised study documented a higher incidence of inhibitor development among PUPs treated with recombinant factor VIII compared to those treated with plasma-derived products which contained von Willebrand factor. Change of treatment product (for example after a national tender) has not been shown to increase the risk of inhibitor development in previously treated patients (PTPs). Discussions on treatment options should take place with the parents of PUPs before starting treatment.

In patients with non-severe haemophilia A, the risk of inhibitor development does not reduce after 50 EDs and there is life-long risk. In patients with non-severe haemophilia A the risk of inhibitor development seems to be much lower, but when exposure days are taken into account the risk increases up to 13% at 100 ED.

## EARLY RECOGNITION, DIAGNOSIS AND SCREENING

Early recognition and accurate diagnosis (detection and titration) of inhibitors are essential for successful management and planning optimal treatment. If an initial inhibitor screening test based on an APTT (activated partial thromboplastin time) mix is positive, the result should be confirmed by performing a Bethesda assay with the Nijmegen modification on a fresh sample and the patient monitored closely in the meantime.

Not all Haemophilia Treatment Centres have the necessary laboratory facilities to perform these assays. The NMO should be able to facilitate referral of the patient to a laboratory in an expert centre, e.g. by having contact information at hand of the treatment centre where these assays can be carried out.

All previously untreated patients (PUPs) should be closely monitored and regularly screened for inhibitors. It is also recommended that periodic screening should continue to be performed as part of the routine follow-up process on an annual basis, as well as prior to surgery, before and some weeks after a switch in clotting factor concentrate. It is essential for patients and treatment centres to keep records relating to product usage.

Recent studies have highlighted the risk of inhibitor development after intensive treatment of patients with mild and moderate haemophilia. In light of this, it is recommended that patients with non-severe haemophilia A should be proactively screened for inhibitors approximately 6 weeks after surgery or treatment for a major bleed.

In the case of haemophilia B, it is recommended to perform a DNA analysis to identify the underlying genotype. This will help identify patients at a higher risk for inhibitor development. Inhibitor development in patients with haemophilia B is often associated with anaphylactic reactions. In cases where a high risk is identified (e.g. large gene deletion), or if the genotype is unknown, precautions may then be taken such as ensuring that the first 20 or so infusions are only given in a hospital setting with close monitoring.

## TREATMENT OPTIONS

In contrast to what is available to haemophilia patients without inhibitors, the treatment options available for patients with inhibitors are very limited. While prophylactic treatment is the optimum for patients with bleeding disorders, prophylaxis or even treatment of bleeds in people with inhibitors is more difficult, as choosing the optimal treatment depends on many factors, including the inhibitor titre, the site and severity of the bleed and whether a patient is about to undergo immune tolerance induction (ITI) therapy.

### Bypassing agents

To this day bypassing agents are the mainstay of prophylaxis and treatment of bleeds in people with inhibitors. The role of bypassing agents is to work around inhibitors to promote clotting. Currently there are two available bypassing agents- activated prothrombin complex concentrate (aPCC) (FEIBA®, Takeda) and recombinant activated factor VII(rVIIa) (NovoSeven®, Novo Nordisk).

Both products have shown to be similarly effective in treating patients with inhibitors, however some patients seem to respond to one agent better than the other. Therefore, it is advisable for haemophilia treatment centres to have both products readily available.

NovoSeven® is regarded as the preferred product for treatment of bleeds before starting immune tolerance induction as FEIBA contains trace amounts of FVIII which may promote an anamnestic response and rise in inhibitor titre.

### Non-replacement therapies

There are new strategies that provide a prophylactic effect, but without the use of factor concentrate. These have two main potential benefits. Firstly, as there is no actual clotting factor infused, inhibitor development is not triggered. Secondly, they use subcutaneous delivery and have longer half-lives, which allow for weekly to monthly dosing. This may also assist with compliance.

One of these non-replacement therapies, suitable for patients with haemophilia A and inhibitors is emicizumab (Hemlibra®, Roche). It is a bispecific antibody that bridges activated factor IX (FIXa) and factor X (FX) in order to restore the function of the missing activated FVIII (FVIIIa) that is needed for effective haemostasis. Prophylaxis with emicizumab is now regarded as the optimal therapy in patients with persistent inhibitors. Clinical studies have demonstrated superior outcomes with this agent compared to previous treatment regimens with bypassing agents alone.

## Immune Tolerance Induction (ITI)

Currently the only way to eradicate inhibitors is Immune Tolerance Induction (ITI). Successful ITI means that the body's immune system no longer treats the infused coagulation factor as a threat. Thus, ITI therapy offers an opportunity to return to standard treatments (such as prophylaxis with clotting factor concentrates), which become effective again upon disappearance of clotting factor-neutralising antibodies. Approximately 30% of inhibitors can be eradicated this way.

ITI therapy involves frequent infusions of high doses of the deficient clotting factor over an extended period of time – months or even years – challenging the patient's immune system to accept the infused factor concentrate. ITI is usually started with the same product that was used when inhibitors developed. There are several ITI protocols available.

To ensure the best outcome of ITI, it is important not to interrupt regular infusions. ITI is a demanding, resource-heavy treatment and as such modalities, implications and success rates, as well as the patient's suitability, should be discussed before starting. The NMO can be a great assistance and support for patients and their families in the preparation and process of ITI.

Even in light of the development of non-replacement therapies that are suitable for people with inhibitors, the consensus among clinicians still is that the eradication of inhibitors is the best outcome for patients with inhibitors.

## Additional therapies

**Plasmapheresis** allows to quickly reduce the inhibitor titre in the patient's plasma, which allows a temporary use of clotting factor concentrates to control bleeding before the inhibitor titre builds back up. This method requires specialised equipment that takes blood out of the patient's body to separate the plasma from the blood cells and extract the inhibitor from it. Therefore, plasmapheresis is usually only done before surgery or when bleeding cannot be controlled using bypassing agents.

**Tranexamic acid** is an antifibrinolytic drug, which keeps the blood clot from breaking down and thus lowers the risk that bleeding will resume. Tranexamic acid does not stop the bleeding as such, so it cannot be used as a stand-alone therapy to control bleeding. However, it is a useful additional therapy, particularly in external bleeding from mucous membranes (dental procedures, nosebleeds). It should not be used in combination with aPCC.

Currently there are non-replacement treatment options being investigated that will also be suitable for patients with haemophilia B and inhibitors. Those include the inhibition of Anti-Thrombin (AT), a tissue factor pathway inhibitor (TFPI) and activated protein C (aPC). The idea of these treatments is to restore the balance of the clotting system, by reducing the level of the anticoagulants instead of increasing the level of clotting agents. The advantages of those treatments are that they are administered subcutaneously and do not require frequent injections.

## IMPORTANCE OF COMPREHENSIVE CARE

Haemophilia, especially when burdened by inhibitors, requires complex and life-long medical care. Besides haemostatic treatment, it also involves accurate diagnosis, as well as management and supervision of a variety of medical and psychological aspects that affect patients and their caregivers and families.

Therefore, the basic comprehensive care team should include multidisciplinary experts - a haematologist, nurse, musculoskeletal experts (physiotherapist and/or orthopaedist), laboratory specialist and a psychosocial expert. All of these specialists should have received appropriate training in the management of haemophilia (with inhibitors). In addition to these experts, access to experts such as dentists, hepatologists, infectologists and gynaecologists should be ensured, if they are not directly included in the multidisciplinary care team.

These experts should be available for treatment of bleeds and complications, as well as to support and supervise home treatment programmes. The comprehensive care programme should also include access to 24-hour emergency medical care.

Patients with haemophilia and inhibitors, especially newly diagnosed families, are often not aware of all the elements of care that constitute comprehensive care and thus optimal management of the condition. The NMOs can play an important role of support by providing basic education about the condition (e.g. a small brochure and a face-to-face meeting to explain the brochure) and optimal management, as well as ensuring the patients and their caregivers are connected with the comprehensive care centre.

If there is no comprehensive care centre in the country or the region, the NMO could establish and maintain a contact list of relevant multidisciplinary specialists who have an understanding about haemophilia (with inhibitors) and its treatment. NMO can also play an active role in providing knowledge to healthcare professionals by creating a small publication aimed at this group.

An important part of comprehensive care is active involvement of the patient to ensure an ongoing improvement in treatment and care, including contribution to research and innovation. Due to the small numbers of people with inhibitors, it is more challenging and time consuming to collect data and perform any kind of research. However, improvements in clinical outcomes for inhibitor patients will increasingly depend on future research and innovation. Therefore it is highly desirable that patients with inhibitors are registered with treatment centres where innovations and contribution to research are accessible.

Up-to-date information about the timeline and enrolment procedures of clinical trials is available on the website of the EUHANET project ([www.haemophilacentral.org](http://www.haemophilacentral.org)) and should be further disseminated by patient organisations.

Pharmacovigilance is an essential aspect of innovation in terms of patient safety. Adverse event reporting through the European Haemophilia Safety Surveillance (EUHASS, [www.euhass.org](http://www.euhass.org)) platform should be encouraged by healthcare professionals and patient organisations.



## MAIN CHALLENGES

Having in mind the rareness and severity of the condition, people with inhibitors face a specific set of challenges. Understanding and recognising these challenges can help the NMOs to provide relevant support to those in their community who are affected by an inhibitor. The challenges outlined in this publication are based on the information collected in the needs assessment survey of more than 200 persons affected by an inhibitor that EHC carried out in 2016.

### **Lack of information about the condition and treatment options**

Haemophilia with inhibitors is a rare condition within a rare condition and there is not a lot of information available in a language that is easily understandable for patients, especially when there is no previous family history. This can be a shocking experience that creates a lot of insecurity and anxiety.

Healthcare providers who may be the patients' primary source of information may have very limited time per patient and therefore no time to go into detailed explanations, or if there is enough time, the explanation can be in a complex medical language. Especially now, when more new treatment options are appearing, it is crucial to educate patients about them.

The NMO can be a great support in overcoming this challenge by providing a simple brochure (or alternatively a section on their website, or both) in a local and patient-friendly language and a list of useful links in English to help explain the condition and treatment options available.

Establishing a good working relationship between the NMO and a healthcare professional (doctor or nurse) can be helpful and eventually online/phone/face-to-face meetings can be arranged to provide information to patients and parents.

The European Inhibitor Network can be a good source of information, both in terms of information and specialist advice, but also in terms of peer support.

### **Difficult medical management**

Difficult medical management is among the most challenging issues that the PWI and their caregivers have to face. Not only are treatment options very often scarce, but also frequent infusions and vein puncture can be problematic for a variety of reasons, such as needle phobia and difficult veins. These issues can be addressed by using central venous access devices (CVADs), such as port-a-cath and broviac catheters. However, this solution can bring additional worries and a risk of infections.

The NMO can play a role in overcoming these challenges by facilitating a (self-)infusion training for PWI and their caregivers, as well as having a good relationship with healthcare professionals to ensure they would be available for consultations or a question-and-answer session.

## **Isolation and potential barriers to participation**

Living with haemophilia and the additional burden of inhibitors can bring about quite a lot of isolation caused by a variety of barriers to participation, such as mobility difficulties, frequent visits to hospital or chronic pain. All of these can impact one's access to education and jobs, social life and romantic relationships.

In addition, the small numbers of PWI in a country and potentially large geographic distances to cover, may create a feeling of isolation from others and a feeling of being trapped in one's immediate environment.

Establishing a WhatsApp or other social media group can help in overcoming the isolation and encourage more participation from PWI. Also, providing advice on career issues can be of great value.

## **Challenges in everyday activities**

Many PWI, especially those from an older generation, suffer from joint damage that leads to mobility difficulties and chronic pain. Thus it can prove very challenging to perform everyday activities, such as dressing oneself, brushing teeth, showering etc.

To address these challenges, the NMOs could provide simple solutions, such as offering information about home adaptations or assistive technology (see Useful links section) that may ease everyday activities of PWI.

Another idea may be creating an intergenerational twinning programme, where youth affected by inhibitors help the older PWI with their everyday activities, such as shopping or other simple chores, whereas the older generation could share their life experiences and advice on a variety of issues that seem challenging for younger PWI.

## **Psychological and emotional discomfort**

Some of the psychological challenges experienced by PWI and their caregivers are stigma, loss of hope, no control over one's condition, the unpredictability that is characteristic in the lives of those affected by inhibitors as well as guilt for parents.

Being aware of these challenges can help the NMO tailor the services and programmes offered to PWI. Sometimes no complicated and expensive solution is needed and a simple conversation (among peers) can be valuable.

## **Medical**

In the survey some medical challenges other than managing haemophilia with inhibitors appeared. For example, difficult access to dental and other surgical interventions, as well as the absence of a cure, can result in psychological distress and challenges.

There are several publications and materials about access to, and management of, surgical interventions in people with haemophilia with inhibitors, that demonstrate the possibility of safe surgery in PWI. The NMO can be seen as a liaison between the healthcare professionals that are not specialised in haemophilia and provide them with the relevant information in the language that is understandable to them about the condition and management of invasive procedures.

## **Systemic**

Some of the challenges outlined in the survey responses could be classified as systemic challenges. Among those are such things as lack of understanding and ignorance from healthcare professionals, but also sometimes from the NMOs. Especially in countries where there is good access to treatment for haemophilia patients without inhibitors, it can create a gap in the membership of the NMO and a perceived lack of understanding. This can be addressed by ensuring that all members of the NMO are at least minimally informed about the challenges faced by people who are living with a variety of bleeding disorders.

## **Value in participation**

The respondents to the survey were also asked what kind of value is achieved by active participation in the life of the NMO. The responses indicate that a simple acknowledgment from the NMO and the desire to start addressing the above-mentioned challenges would be positive, for example by simply bringing people together as the NMO events can offer the PWI things like learning and new information, understanding, sharing and exchanging, moral support, motivation and empowerment, support in the management of inhibitors and motivation for physical activity.

# CHAPTER 2



**WHO IS AFFECTED BY  
INHIBITORS IN YOUR COUNTRY?**

## WHO ARE THE PEOPLE AFFECTED BY INHIBITORS?

For many years, when speaking of bleeding disorders, the focus has been mainly on the person with the bleeding disorder (in this case – with the additional burden of inhibitors), which predominantly is male. But this male may also be a husband, a son, a father and a brother. Furthermore, bleeding disorders and inhibitors affect not only men- females can also acquire an inhibitor. In this chapter we will identify who are the people affected by inhibitors in your NMO and the particular challenges they face.

The ripple effect of living with a bleeding disorder and inhibitor goes far beyond the person with inhibitors him/herself- also the family members and caregivers are affected in different ways.

Depending on where the person with inhibitors lives, one of the major challenges for someone with an inhibitor may be the lack of access to effective treatment, including new treatment options that have become available in the past year. This situation further creates the likelihood of people with inhibitors and their families and caregivers to experience more physical and psychological issues than patients without inhibitors. This can be often compounded by a lack of insight or understanding into the effect it has on them.

More concretely, people with inhibitors or their families and caregivers may have experienced at some point or are currently experiencing:

- **Isolation** (physical and/or psychological);
- Impact on **mental wellbeing**;
- **Anxiety** and worry about the potential side effects of new treatment products, particularly by parents or partners of PWI;
- A **lack of understanding** from other/ extended family members;
- **Lack of understanding and support** from employers when requiring time off work to care for a child or partner;
- **Financial hardship** from missed education/employment due to caring for a family member;
- **Lack of support**;
- **Not being able to share** common issues with people in a similar situation;
- **Neglect in self-care**;
- Encountering **healthcare systems that do not provide**, or do not have the resources to provide, access to services and treatments specifically designed for the needs of a person with inhibitors.

Supporting people with inhibitors, their caregivers and families in overcoming many of these challenges often does not require financial resources from the NMO. Harnessing the creativity and power of dedicated volunteers can be sufficient for laying foundations for the better inclusion of people with inhibitors in the life of the NMO.



### **M – Ireland.**

Wife of older male with haemophilia and an inhibitor.

Living with somebody who has severe haemophilia and an inhibitor requires a lifetime of vigilance as bleed symptoms are not always apparent. Knowing the person well means being in a position to notice subtle changes in behaviour, etc. This is not always matched in the medical community and sometimes one worries about a lack of understanding. The responsibility to act quickly and responsibly rests with oneself. With older haemophiliacs, support networks were not there when a crisis arose and at no time was I or the family offered counselling or psychological support.

### **H – Finland.**

Woman with VWD and an inhibitor.

My bleeding disorder was only discovered and got a name when I was six years old, in the year 1956. The biggest problem for me has been bleeds into the joints, from which, as a result, I have had very bad joints as an adult. When I was almost 20 years old, there was finally a medicine for bleeds, but very soon it was discovered that it did not help and an inhibitor was diagnosed.

Without a treatment for the inhibitor but with huge amounts of factor concentrate, I have given birth to two healthy children and have had orthopaedic operations. Starting from 15 years ago, I have been allowed to use medicine at home against joint bleedings and now I can take it prophylactically. For four years now, I have successfully been treated to weaken the inhibitor. Now I am 66 years old, still working as an eye doctor and a happy grandmother of my son's son.

### **M – Serbia.**

Adult with haemophilia and inhibitor.

Haemophilia has always been a "limiter" of joy and contentment for me and my family. Psychosocial support would be beneficial to show us how we should cope with it.



### **T – Portugal.**

Mother of two sons with haemophilia and inhibitors.

Being a mother of two boys with severe haemophilia A and inhibitors, one aged 12 and the other aged five, is not an easy task! We never know how the day will start! It is frequent that they go to sleep well and wake up with some kind of bleed that completely messes up our day! The uncertainty is high, and therefore, for our mental health psychological support is fundamental. Also, the involvement of all family members in the condition is important. Talking and sharing our issues with other families with the same condition, or that are simply our friends, is very important for social support and integration. Do not be isolated! Being part of the Portuguese national organisation for bleeding disorders also helped improve our happiness and as a family we are completely integrated as members of the organisation.

### **I – UK.**

Older sister of boy with an inhibitor.

As an older sister, I have only noticed big changes since his new medicine. Before, it was normal that plans could change at the last minute. Instead of going to Legoland we would go to the hospital. I thought that was normal. It has also been cool for my brother to have haemophilia. I have been invited to cool days out: flown planes, learnt fencing, special weekends away. And although I know that my friends who also have brothers love one another, perhaps because of what we have been through together, I have a special relationship with my brother and we have a deep love for each other.

## WHAT ARE THE ISSUES THEY EXPERIENCE?

### Newly Diagnosed Families – special focus

Many parents, in addition to expertise from health professionals, also want opportunities to meet other parents. This is especially important if they are the parents of a newly diagnosed child with haemophilia and particularly haemophilia with inhibitors. Having just discovered that your child has an inhibitor is a very vulnerable time for parents and for the whole family. They will almost certainly experience fear for the future and worry about how they will care for their child.

Fathers would benefit from tailored events which give them the opportunity to open up about feelings they sometimes suppress, e.g. dealing with the fact that their sons may not be able to follow the paths in life that their fathers have envisaged for them, or to do 'manly' things. Mothers often need support to deal with feelings of guilt. Both parents will experience a roller-coaster of emotions. Events aimed at providing improved support, both from a medical and psychosocial point of view, would enable parents to become better advocates for their children. Also, providing knowledge around treatment options and how they work, would be beneficial as this would help improve the confidence of parents. In addition, the sharing of experiences about 'How to manage day-to-day life' between newly diagnosed parents and more experienced parents would be very helpful and give the newer parents more reassurance and hope for the future.

### Parents, partners and caregivers

The impact, if you are the parents, partner or caregiver of someone with an inhibitor, reaches greater heights than for a family not affected by an inhibitor. It is a sustained cycle of worry. Even with the new treatments available there is constant fear that this treatment might fail and your child or partner has to return to less effective treatment regimes. There is added stress and uncertainty around surgery and dental care, and the fear of the unknown and the possibility of trauma.

In addition, families often have to live with the consequences of physical impacts PWI attending countless hospital visits and feeling helpless when factor hasn't worked. There is an increased effect on siblings, who often have to relinquish activities and might experience, through no-one's fault, less attention than the affected brother or sister. Always having a 'Plan B' ready is very useful for the whole family and is a very helpful tool in reducing the frequent frustration you might experience when having to change plans. The new treatments are giving hope for the first time.

There is a strain on the parents of a child with inhibitors in terms of their relationship as a couple. Caring for their child adds a great amount of stress and takes up excessive amounts of time, leaving no time or energy to maintain the couple's relationship. In addition to this, it is often very hard to find somebody willing to look after/babysit the child even for a few hours while the parents are out on a date.

This could be a simple (voluntary) service offered by the NMO, where teens or older people with haemophilia, thus having the right knowledge, would occasionally support the parents of children with inhibitors by allowing them to go on a date night.

For children with haemophilia and inhibitors, attending school can be challenging due to potential frequent absences, as well as fear from teachers, which may lead to isolation and overprotection for the child with inhibitors. Flexibility and understanding within school environments, as well as from employers and work colleagues, is very important due to the frequent absences person with inhibitors might need to take from work for hospital visits. Here the NMOs can play an important role by providing basic information about haemophilia and inhibitors, as well as about the management of the condition.

## **Data Protection Issues – how to reach out?**

With today's requirements for data protection it is not easy to reach out to those affected by an inhibitor. Often the NMOs have no means to obtain information as to how many people with inhibitors there are in their country, even in collaboration with the local Haemophilia Treatment Centre (HTC). In these situations, the only way to reach out is to ensure enough visibility for the NMO and the support offered to people with inhibitors and their caregivers and families, so that those affected by an inhibitor would want to contact the NMO and benefit from the support offered. There are several ways how this can be done.

NMOs can make a positive difference by creating flyers to distribute to the Haemophilia Treatment Centres in their countries, describing the work of the NMO and the support offered, and asking anyone with an inhibitor to make themselves known to the NMO. This is especially effective if the NMO has elected an EHC Inhibitor Ambassador. The Inhibitor Ambassador, by having a profile and a contact address, is a more visible advocate and will make it easier for that country's NMO to reach out to new PWI, their caregivers or their families.

Alternatively, a personalised letter can be written by the EHC Inhibitor Ambassador, who very likely also is a person affected by inhibitors, which can be given to the patients or the parents directly by the healthcare professional during the visit. Also, an attention-drawing poster can be placed in the waiting room, if the rules of the Haemophilia Treatment Centre allow this.

If the financial or human resources (a member of staff or a volunteer, e.g. Inhibitor Ambassador) of the NMO allow it and the relationship with the Haemophilia Treatment Centres and healthcare professionals is well established, the NMO presence in the treatment centre once or twice a week can be considered. This way those who visit the treatment centre have also an opportunity to engage directly with the NMO.

Through engaging and participating in the events organised by the EHC and its European Inhibitor Network (EIN), the Inhibitor Ambassador can promote important sources of support and information to the families in its NMO's network. The Haemophilia Treatment Centres can also contribute by promoting the EIN and encouraging patients to engage with their NMO. This is all possible without having to breach data protection.

## PROVIDING MEANINGFUL SUPPORT

As described above the various people affected by inhibitors have different needs. To provide meaningful support to all of those different people means a good understanding of their needs and offering diversified support that matches those needs. This does not have to be complex or expensive.

Ideally, a self-sufficient inhibitor working group or network should be established within the NMO, ensuring the support needed is in place.

### Examples of meaningful support

| Target group                                 | Need/challenge  | Support offered  |
|--|---|--|
| Newly diagnosed family                       | The shock of a new diagnosis and need for basic first information.                                | <b>Basic inhibitor information sheet:</b> information about inhibitors and treatment options with contacts of HTC and useful links for further reading (see <b>Useful Links</b> section), as well as a contact phone number of some support person. This does not have to have fancy design or print – information is the most useful and necessary, so even a simple A4 print will do.  |
| PWI  | PWI often experience anxiety and depression due to the complicated nature of their condition.     | <b>Psychosocial advice to PWI:</b> in very few countries psychosocial support is provided by the HTC. The NMO could make simple provisions to provide this service, for example by engaging a psychosocial specialist that would lead a peer-to-peer group for PWI on a regular basis.   |
| Mothers/ fathers of children with inhibitors | Feelings of isolation and helplessness, need of advice.   | <b>Peer-to-peer encounters for parents:</b> this could be just an afternoon coffee or a simple meal together. It is important to start the contact. The role of the NMO in this case would be to serve as a middle-man to set the date, make reservations and spread the information. For the first and second meetings it may be useful to have someone from the NMO board present (woman for the mothers and man for fathers). |
| PWI, caregivers and families                 | Physical isolation and difficulty taking part in face-to-face meetings due to various challenges. | <b>Social media groups:</b> A peer-support network is a useful and effective way of reducing isolation, especially if one lives a long way from the HTC or NMO office. With email, social media and mobile phones, these PWI, caregivers and families that are physically  |



| Target group                              | Need/challenge   | Support offered  |
|---|--|--|
|   |  | more isolated can be part of a helpful and mutually supportive, relevant network. Separate groups can be created for PWI, parents and caregivers.  |
| PWI who are young adults                  | Teenagers and young adults with chronic conditions often experience the pressure to feel 'normal' among their peers.   | <b>Film evenings and hanging out together:</b> a simple film evening can be organised in the headquarters of the NMO, with soft drinks and popcorn. The youth could bring their non-haemophilia friends too. Not talking about haemophilia or inhibitors, but just hanging out, might help highlight their 'normality.' If the NMO does not have any facilities, one might explore the idea of approaching other NGOs or workplaces of the members of the community.   |
| Parents of young children with inhibitors | Very often parents of young children experience the difficulty of being able to find the time for their life as a couple. Having a child with inhibitors may add to the difficulty of being able to find a babysitter (even a relative) willing to care for the child for a couple of hours. | <b>Inhibitor-friendly baby-sitting service:</b> if the geographical setting allows, the NMO could provide a pool of volunteers (or paid babysitters) from the members of the community who would have experience with bleeding disorders and be available occasionally to look after children with inhibitors while their parents enjoy a date-night. This pool could consist of parents of older/grown children with inhibitors or siblings of PWI.   |
| All who are affected by inhibitors        | Lack of information about treatment options.   | <p><b>EHC, and in particular the EIN:</b> offers a series of opportunities to obtain information about the latest in inhibitor treatment and management, for example the Inhibitor Summit and EIN online activities, as well as EHC Round Tables on various themes. The NMO should consider occasionally sending those affected by inhibitors to these events, as well as to provide feedback to all the membership after someone from the NMO has attended.</p> <p>Also, the NMO itself could organise round tables or panel discussions with the health-care professionals to give updates on these themes. If the NMO does not have the facility for this, a room in the HTC could be asked for or other NGOs approached.</p> |

There are plenty other things that can be done!

**You will almost definitely get more ideas after talking to those affected by inhibitors about what their needs are!**

# CHAPTER 3



**ORGANISING AN EVENT  
FOR PEOPLE AFFECTED  
BY AN INHIBITOR**



## ORGANISING AN EVENT

In the previous chapters we considered some ideas that could be implemented to overcome the challenges that PWI, their families and caregivers are facing. In this chapter we will build on those and move towards a notion that bringing the people who are affected by inhibitors in your NMO and eventually in your country, together, is the best foundation for a supportive and inclusive NMO when it comes to people with inhibitors.

By coming together people get challenged, inspired and empowered to contest their status quo; challenged to go beyond their comfort zone and take calculated risks when it comes to active participation; inspired by encountering each other and seeing the struggles and victories of others who are in a similar situation as they are; empowered to request the adequate treatment and care that they deserve.

### Have a plan!

In order to offer meaningful support to PWI and their caregivers in your NMO through an event, it is necessary to carry out a thorough needs analysis first. Do not do something only because you want to do something. Ask: What are the problems? What are the needs of the PWI? What are the needs of caregivers and family? Sometimes the real needs are not visible at once, you may need to dig deeper.

In a needs analysis you might discover multiple needs and problems. But by trying to do everything you might achieve nothing. Choose and prioritise! Eventually there will be a possibility to address other needs. At this point it may be also relevant to list and consider the organisational variables involved- the NMO capacity in terms of finances, human resources, the number of PWI/families in the NMO- and how to organise the event to meet the needs identified with these variables in mind.

It is important to remember that it is fine to start small. Because *‘There is only one way to eat an elephant – one bite at a time’!*

### Adding perspectives of various stakeholders

To add diversity to the themes and information offered to PWI and their caregivers, the NMO may explore adding the perspectives of various stakeholders. People may have a variety of questions and needs, therefore offering a diversity can be beneficial.

In addition, stakeholders like NMO leaders, multidisciplinary care experts, those who make the decision about treatment products available, PWI, their caregivers/families all have a different outlook on the needs of PWI and how to meet them. Therefore, adding the perspective of these stakeholders to the programme or at least the planning of the event, can greatly enrich it. This can be done as a simple one-time consultation process or involving the various stakeholders in the organising committee of the event. In the long term it can also help the NMO establish better collaboration with the healthcare professionals and government agencies.

| Things to consider                                  | Questions to answer   |
|---|---|
| Defining aims, objectives, context and target group | <p>In what <b>context</b> will the event take place?</p> <p>What <b>needs</b> will it meet and what <b>changes</b> will it bring?</p> <p>What is the expected <b>result</b>? In the short and long term?</p> <p><b>Who</b> is the event designed <b>for</b> - who will be the participants? If there will be multiple target groups (e.g. PWI and caregivers), how will the needs of each be met?</p> |
| Content of the event                                | <p>What is the <b>theme</b> and <b>content</b> of the event?</p> <p>What is the chosen approach (<b>methodology</b>)? What <b>activities</b> are involved?</p> <p>What is <b>needed</b> for the event to go ahead?</p>  |
| Where and when                                      | <p><b>Where</b> will the event take place?</p> <p><b>When</b> does it start/end? What will be the <b>daily time frame</b>?</p>  |
| Practicalities                                      | <p>What <b>logistics</b> are required?</p> <p>What <b>practical matters</b> must be dealt with?</p>   |
| Funding   | <p>What is the overall <b>cost</b>? (planning, implementation and evaluation),</p> <p>Where will the necessary <b>funding come from</b>?</p> <p>Can <b>existing resources</b>, facilities, conditions be used, e.g. NMO headquarters, volunteers?</p>   |
| Partner   | <p><b>Who</b> are the partners?</p> <p>What is their <b>role</b>?</p> <p>What are the arrangements for <b>coordination</b>?</p>   |
| Communication                                       | <p><b>Internal</b> communication: how does information circulate within the event team?</p> <p><b>External</b> communication: How will the event be communicated externally? How will the participants be recruited? Does the event need media coverage? (Why? How? Which aspects?)</p>   |
| Evaluation and follow-up                            | <p><b>How and when</b> should it be evaluated?</p> <p>Which aspects? Why? What <b>follow-up</b> is planned?</p>   |

## HAEMO-FRIENDLY PRACTICAL ARRANGEMENTS

When organising an event for those affected by inhibitors, it is important to keep in mind certain arrangements that will make participation easier for people with inhibitors.

### Planning of the event

Ideally, there should be someone affected by inhibitors (PWI, parent or caregiver) on the organising committee of the event. This way it is easier to ensure that the arrangements are made correctly.

### Transportation

Among the biggest challenges for people with inhibitors are physical isolation and mobility difficulties. When organising an event for people affected by inhibitors and choosing the venue, think how accessible it will be for them. If needed, seek to provide special transportation for those with mobility challenges, e.g. using a wheelchair or using crutches. If the NMO itself does not have the resources to provide this service, cooperation with other organisations providing such services (e.g. Maltese Order) can be considered.

### Accommodation

People with inhibitors may have different needs when it comes to accommodation, e.g. some might prefer a walk-in shower, while others a bathtub. Before assigning accommodation, if the resources allow this choice, make sure to find out what the exact needs are. If there is limited choice of facilities, think of simple adaptations that can be made, e.g. anti-slip bath mat or a chair in the bathroom that can be put in the shower. Also, if the resources allow, ensure that the room is big enough for moving around comfortably.

### Venue

There are two main issues that may pose a problem in terms of venue – long distances to walk and stairs. When choosing a venue, make sure that there is no need to take the stairs, or that the venue is equipped with an elevator that helps people with mobility challenges reach all the parts of the venue that you will be using. It is also essential that there is a staff person on call that can deal with situations if an elevator breaks down.

### Programme

When organising an event for people affected by inhibitors, be mindful of additional discomfort that they may be experiencing due to the chronic pain, thus making sitting down for a long time difficult. Make sure that the sessions do not last too long (an hour or an hour and 15 minutes can be optimal).

## THERE IS ONLY ONE PERSON - WHAT TO DO?

Often the NMOs face the challenge that seems difficult to overcome – there are only a handful, if not less, PWI in the country. In addition to that, the factor of unpredictability of having an inhibitor means that an event intended for 10 participants may end up having only four. Are there ways to work around these obstacles? In the experience of the EHC, adding the numbers up can be the answer.

A good first step, that would not take resources and organisational energy, would be participation of PWI in the European Inhibitor Network. This will allow PWI to share their experiences with others in a similar situation, but will require very little effort from the part of the NMO.

Also, a variety of online activities can be explored – question and answer sessions with healthcare professionals, parent or peer-to-peer discussion groups on Skype, or simply a social media group to keep in touch.

Finally, an option that has proved to work quite successfully is regional cooperation\* in organising events for PWI, which is especially efficient in regions where there is a common language. Below we are happy to present an example from the Serbian Haemophilia Society.

### Good practice example: National & Regional Inhibitor Camp Serbian Haemophilia Society

The Serbian Haemophilia Society has been organising a National Inhibitor Camp since 2013. In 2019 the seventh National and first Regional Inhibitor Camp took place in Belgrade, Serbia.

#### How is the project implemented/organised?

##### What?

Having a small group of people with a specific problem of inhibitors, a lack of support and feeling isolated, resulted in an idea to organise a camp for those people. Gathering all people that have the same issues to exchange and share ideas on how some of these problems can be overcome, as well as educating them, was found to be more than useful.

The National Inhibitor Camp is a huge opportunity to empower PWI and provide them with additional information. Like in any project, education, the ability to communicate with their doctors and among themselves, is essential during the weekend. In the camp setting everybody feels that they are in a safe environment, they feel relaxed and that they can speak freely.

In terms of the Regional Camp, it was felt that the Balkan region altogether has a very small number of PWI, so it was decided to extend the invitation to other Balkan NMOs to take part in the camp.

## Who? For whom? With Whom?

The National Inhibitor Camp is organised by the Serbian NMO for adult PWI, together with health-care professionals from all HTC, who work daily with PWI. They are included in the activities of the camp through the medical sessions and panel discussions. An important part of the camp are the nurses, they give their support on site with treatment and provide education on self-infusion. Some of the patients are very old and cannot treat themselves with bypassing agents, so the nurses help and show them how to find veins and how to inject properly.

## Why?

The most important part is establishing a connection between the PWI and building a community. This way we can include them in the NMO and help them overcome social barriers caused by mobility issues. Most PWI in our NMO have mobility issues and do not have much possibility to socialise in their daily life and to have a normal social life. That is why this small part of the year when the camp takes place is the time when they can feel like themselves and they can see that there are other people who experience the same problems and see how others cope with those problems.

## How?

The National Inhibitor Camp is a four-day event. On Thursday afternoon we welcome participants, the medical staff and someone from the NMO is on site to welcome them. On the agenda there are various medical and educational sessions – mostly they are related to inhibitors, e.g. physiotherapy education and practice and we also practice in the swimming pool; orthopaedic surgery, the current possibilities and a recommendation for each patient for orthopaedic surgery; dental care – what should be done for each patient, what are the new technologies in dental care, pain therapy, haematology and upcoming treatments. Also, participants discuss current issues and we offer recommendations on how each patient should be treated. Individual and group psychosocial sessions are offered as well. We had a couple of round tables with discussions between the patients and doctors, for example about on-demand treatment with bypassing agents or the importance of physiotherapy.

The inhibitor camp focuses on a different theme every year, giving people with inhibitors an opportunity to explore in depth certain aspects of inhibitor treatment and care. Among the themes addressed have been dental care, psychosocial support and orthopaedic surgery.

## When?

The Serbian National Inhibitor camp always takes place in spring, i.e. March-April. We try to always do it before World Haemophilia Day. We found it should be done once per year to keep people engaged, because the longer time period between the two camps can result in losing interest in participation.

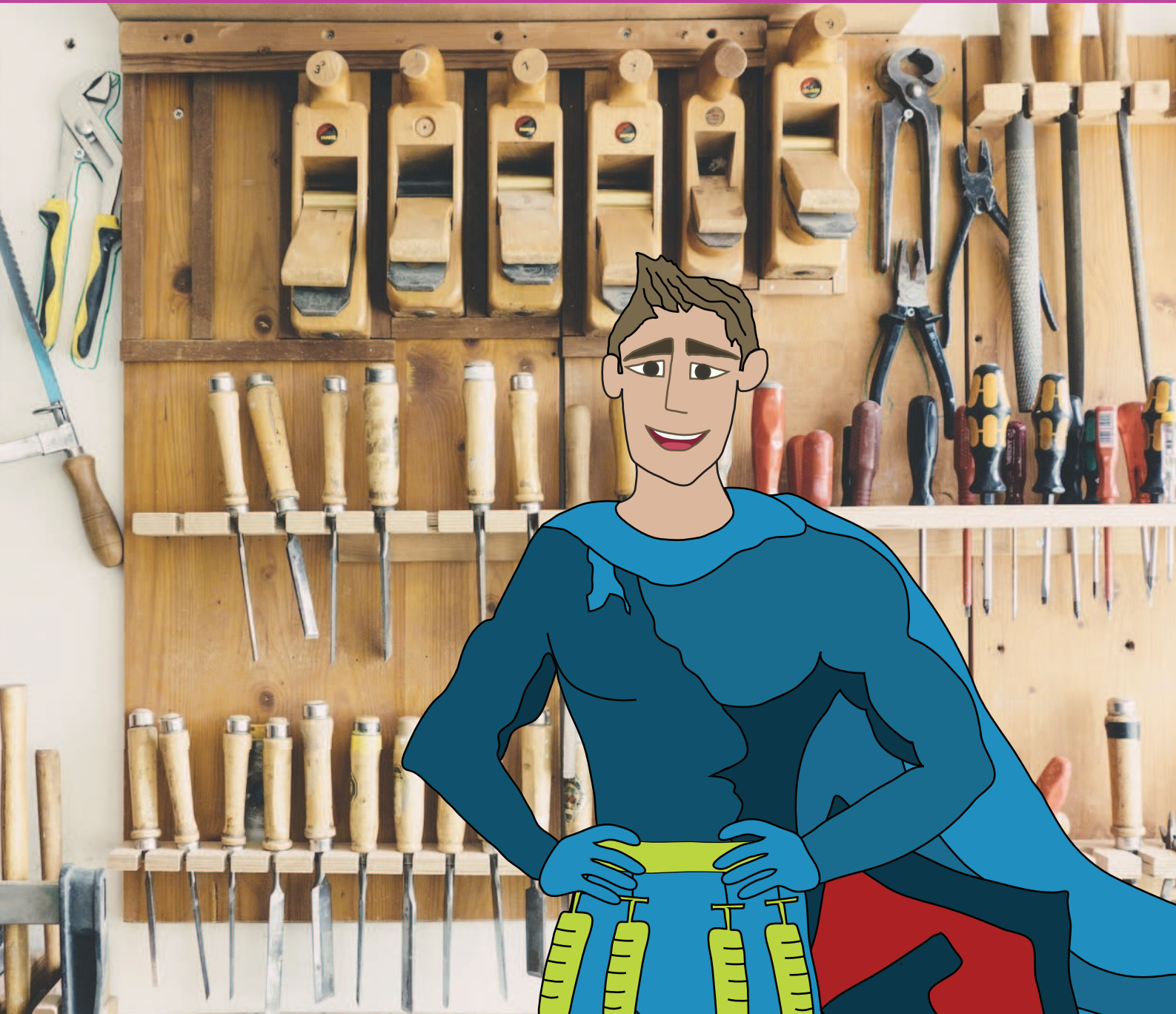
## Where?

It is always held in the same place, in a hotel close to Belgrade. It is very important where the event is held. Most of the participants have on-demand treatment and there is a high risk of bleeding, so the venue should be close to an HTC and it has to be haemo-friendly and accessible for people with disabilities, so that people do not have to walk too much in the hotel.

We had one venue for 5 years, but now we decided to have 2-3 venues and use them in rotation, so that the participants do not lose interest in participating. Because if it is the same place, the same people, the same doctors – it can happen.



# CHAPTER 4



## USEFUL METHODOLOGIES

# HAEMO-FRIENDLY ICEBREAKERS AND ENERGISERS

## ...to learn the names

### Memory name game

Participants stand or sit in a circle. Everyone has to say their name with an adjective in front of it (e.g. Amazing Amanda, Logical Laura, Funny Fiona). The first person to start will say only their combination, whereas the participants to follow will have to say the adjective-name combination of all those before them before saying their own combination. The last person in the circle will have to say the combination of everyone.



*This activity is suitable for a smaller group (up to 20 people) and may take between 10 and 20 minutes, depending on the number of participants. No material is needed.*

## ...and to get to know each other

### Balloon pop

Participants stand in a circle. Ask the participants to put a fact about themselves on a small piece of paper, fold it, and put it in a balloon which they then blow-up. Throw the balloons in the middle of the circle and then have people take turns popping a balloon, reading the piece of paper, and guessing to whom the information applies.



*This activity is suitable for a smaller group (up to 30 people) and may take about 20 minutes, depending on the number of participants. You will need balloons, small pieces of paper and pens.*

### Childhood photos

This activity will require a bit of preparation from participants. Ask them to send you a photo of them as a child in advance of your event. Then give each participant a photo of somebody else (in a bigger group you can divide the participants into smaller groups and give a set of pictures per group). They need to find the person who they think is in the photo and ask them to tell them a story from the time when the photo was taken. Optional – to make finding easier and faster you may write the initials of the person and a clue about them on the back of the photo.



*This activity is suitable for small and big groups and may take about 15-20 minutes. You will need prints of the photos.*

### Common ground

In small groups, ask participants to come up with six things they have in common and then present these to the large group. If there is not much time you can ask them to present only three out of six. Optional – you can ask the group to draw these things on a flip chart and sign it. Then you can put it up in the room afterwards.



*This activity is suitable for small and big groups and may take about 15-20 minutes (10 for discussion and 5-10 for sharing). You will need sheets of A4 paper and pens.*



### Four Cs

Ask each participant to name a cartoon character, a colour, a car, and a cuisine that best describe their personality and explain why. If you have a bigger group, the same can be done in smaller groups and then briefly shared with the rest of the group.



*This activity is suitable for small and big groups and may take about 15-20 minutes (for a bigger group: 10 for discussion and 10 for sharing). No material is needed.*

### Take a candy!

Pass around a bowl of candy and invite everybody to take as many pieces of candy as they wish (but they should not eat them yet!). When the bowl of candy returns to the facilitator, he or she reveals that each participant has to share the number of facts about themselves that corresponds to the number of pieces of candy they have grabbed (it can be funny as sometimes people take a lot). They can keep and eat the candy. Alternatively, toilet paper can be passed around and participants take the number of sheets they think they need.



*This activity is suitable for a smaller group (up to 20 people) and may take between 10 and 20 minutes, depending on the number of participants. You will need a bowl and a bag of individually wrapped candy (the number should be at least double the number of participants) or a roll of toilet paper.*

### Paper airplanes

Everyone makes a paper airplane and writes their name and two questions they want to ask someone else on it. On the signal of the facilitator, everyone throws their airplane into the room, picks up other airplanes, and keeps throwing them. The facilitator says stop after one or two minutes (you might want to take a longer time for a bigger group). Everyone must have one paper airplane. Then they must find the owner of the airplane they have and answer the questions on the airplane.



*This activity is suitable for small and big groups and may take about 15-20 minutes. You will need sheets of A4 paper and pens.*

### Silent ID

Give each participant a piece of paper and ask them to draw pictures of themselves (or that describe themselves in a way) without talking. Then they are to pin their paper on their chest, walk around, and look at each other. Pictures are then collected. The facilitator then shows them one by one and the participants try to identify to whom each picture belongs.



*This activity is suitable for small and big groups and may take about 15-20 minutes. You will need sheets of A4 paper and pens.*

### 2 truths and a lie

Ask participants to write three things about themselves on a post-it. Two should be true and one should be a lie. Then they have to walk around the room and others have to guess which response was a lie and give their reasoning. If the group is smaller the participants can sit in a circle and simply say their three things out loud, while the rest of the group try to guess.



*This activity is suitable for small and big groups and may take about 15-20 minutes. You will need post-its and pens.*

## ... to start the conversation

### Dilemma game (or Where Do You Stand?)

This activity is great to start the discussion on a variety of themes that you want to discuss during your activity.

You will need to prepare a number of controversial statements beforehand (it is important that they are 'black/white' statements to provoke the discussion) – for example 'Haemophilia care has little chance to improve because there is always a barrier between patients and doctors.'

Divide the room into two by drawing (an imaginary) line in the middle with a sign 'I agree' on one side and 'I disagree' on the other. Explain to the participants that you are now going to read out a series of statements with which people may agree or disagree. After the statement is read out they have to take a position, even if they agree or disagree only to some extent. Then take a few arguments from each side to see what is the reasoning of people. Allow participants to move position as they listen to each others' comments.

When you have gone through the statements, bring the group back together for the debriefing.



*This activity is suitable for small and big groups and may take about 30-45 minutes. You will need statements, signs for 'agree' and 'disagree' and space for people to move.*

## ... to start the day in a fun way

### Groups of...

This can also be a fun way to split the participants into smaller groups.

The participants are gathered in the centre of the room. Then ask them to form groups based on characteristics/preferences they have. For example: eye colour (great to be the first as people have to make eye contact), the number of siblings, preference of a movie genre, favourite drink (give options) or sports to watch.



*This activity is suitable for small and big groups and may take about 10 minutes. No material needed.*

### No smiling

Nobody is permitted to smile for a certain length of time. People will start smiling or laughing because they are not allowed to.



*This activity is suitable for small and big groups and may take about 2-3 minutes. No material needed.*

## TIPS FOR MEETING FACILITATION

Facilitation is about helping the group to have an efficient and inclusive meeting. It is also about making sure everyone can be involved in discussions and in making decisions. It combines a series of roles and tasks. Sometimes these are taken on by one person – the facilitator. However, there is no reason why tasks can't be shared between one or more people in the meeting. Good facilitators stay neutral, winning the trust of everyone in the meeting and treating everyone as equals. At no time do they make decisions for the group or take sides in a conflict.

### Key facilitation tasks

Take part in planning a meeting or event. Think about agenda items/programme elements, timings and how to tackle each point.

Prepare the room so it is comfortable and everyone can participate. Prepare materials the meeting might need e.g. paper, pens.

- Introduce the meeting, what it is about and how the meeting works.
- Keep the group to the agenda and decision-making process, if that is the case.
- Keep the meeting focused on one item at a time.
- Help everyone to participate. Keep track of who wants to speak. Draw out quiet people and limit those who talk a lot.
- Challenge aggressive or discriminatory behaviour and put-downs.
- Introduce group work techniques (described below) to make the meeting more efficient and participatory.
- Clarify and summarise points, make sure everyone understands the discussion.
- Test for agreement and get clear decisions made.
- Ensure that action points and decisions are recorded.
- Keep the meeting to time.
- Help the group deal with conflict.
- Listen for underlying issues, concerns or emotions. Help bring them out so they can be dealt with.

### Group work techniques

In this section of the handbook, we would like to propose several techniques for group work. Various forms of group work can be useful in various settings of your NMO work – whether in planning an activity or event for people affected by inhibitors or as a part of the programme in the event. Group work helps harness the creative energy of staff and volunteers and can often provide solutions to situations where no solution could be seen.

#### Brainstorming

Brainstorming is a way to introduce a new subject, encourage creativity and to generate a lot of ideas very quickly. It can be used for solving a specific problem or answering a question.

**Instructions:**

- Decide on the issue that you want to brainstorm and formulate it into a question that has many possible answers.
- Write the question where everyone can see it.
- Ask people to contribute their ideas and write down the ideas where everyone can see them, for instance, on a flipchart. These should be single words or short phrases.
- Stop the brainstorming when ideas are running out.
- Go through the suggestions and ask for comments.

**Note these points:**

- Write down EVERY new suggestion. Often, the most creative suggestions are the most useful and interesting!
- No one should make any comments or judge what is written down until the end, or repeat ideas which have already been said.
- Encourage everyone to contribute.
- If a suggestion is unclear, ask for clarification.

**Wall writing**

This is a form of brainstorming. Participants write their ideas on small pieces of paper (e.g. Post-its) and paste them on a wall. The advantages of this method are that people can sit and think quietly for themselves before they are influenced by others' ideas, and the pieces of paper can be repositioned to cluster together similar themes or ideas.

**Discussion**

Discussions are a good way to discover what peoples' attitudes to issues are. This is very important because, as well as knowing the facts, people also need to explore and analyse issues for themselves. News, posters and case studies are useful tools for stimulating discussion. Start people off by asking "what do you think about...?".

**Buzz groups**

This is a useful method if no ideas are forthcoming in a whole-group discussion. Ask people to discuss the topic in pairs for one or two minutes and then to share their ideas with the rest of the group. You will soon find the atmosphere "buzzing" with conversations and people "buzzing" with ideas!

**Small-group work**

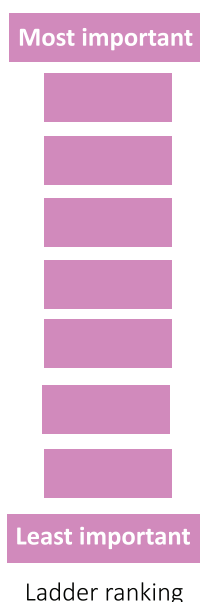
Small-group work is in contrast to whole-group work. It is a method that encourages everyone to participate and helps develop cooperative teamwork. The size of a small group will depend on practical things such as how many people there are all together and how much space you have. A small group may be two or three people, but they work best with six to eight. Small-group work can last for 15 minutes, an hour or a day depending on the task at hand.

It is rarely productive to tell people simply to "discuss the issue". Whatever the topic, it is essential that the work is clearly defined and that people are focused on working towards a goal that requires them to feed back to the whole group. For example, assign a task in the form of a problem that needs solving or a question that requires answering.

## Ranking

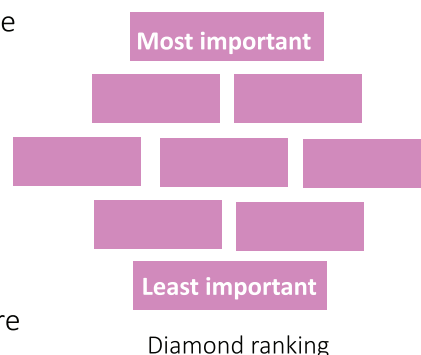
This is a useful method to use when you want to provide specific information or to stimulate a focused discussion in small groups.

You need to prepare one set of statement cards for each small group. There should be nine cards per set. Prepare nine short, simple statements related to the topic you wish people to discuss and write one statement on each card.



Ladder ranking

The groups have to discuss the statements and then rank them in order of importance. This can either be done as a ladder or as a diamond. In ladder ranking the most important statement is placed at the top, the next most important under it and so on to the least important statement at the bottom. In diamond ranking people negotiate what the most important statement is, then the two second-most important, then the three statements of moderate importance and so on as shown in the diagram. Because issues are rarely clear-cut, diamond ranking is often a more appropriate method. It is less contrived and therefore more acceptable to participants. It also gives



Diamond ranking

better opportunities for consensus-building. A variation of the ranking method is to write eight statements and to leave one card blank for participants to write a ninth for themselves.

## Role-play

A role-play is a short drama acted out by the participants. Although people draw on their own life experiences to role-play the situation, it is mostly improvised. It aims to bring to life circumstances or events which are unfamiliar to the participants. Role-plays can improve understanding of a situation and encourage empathy towards those who are involved in it.

Role-plays differ from simulations in that although the latter may also consist of short dramas, they are usually scripted and do not involve the same degree of improvisation.

The value of role-plays is that they imitate real life. They may raise questions to which there is no simple answer, for example about the right or wrong behaviour of a character. To gain greater insights, a useful technique is to ask people to reverse roles.

Role-plays need to be used with sensitivity. Firstly, it is essential that people have time at the end to come out of the role. Secondly, everyone needs to respect the feelings of individuals and the social structure of the group. For example, a role-play about disabled people should take into account the fact that some participants may suffer from disabilities themselves (maybe not visible) or may have relatives or close friends who are disabled. They should not feel hurt, be forced to be exposed or marginalised. If that happens, take it seriously (apologise, re-address the issue as an example, etc.).



Also, be very aware of stereotyping. Role-plays draw out what participants think about other people through their "ability" to play or imitate them. This is also what makes these activities great fun! It may be useful to always address the issue in the debriefing by asking, "do you think that the people you played are really like that?" It is always educational to make people aware of the need for constant and critical reviewing of information. You can therefore also ask participants where they got the information on which they based the development of the character.

### **Simulations**

Simulations can be thought of as extended role-plays that involve everybody. They enable people to experience challenging situations but in a safe atmosphere. Simulations often demand a level of emotional involvement, which makes them very powerful tools. People learn not only with their heads and hands but also with their hearts.

Debriefing is especially important after a simulation. Players should discuss their feelings, why they chose to take the actions that they did, any injustices they perceived, and how acceptable they found any resolution that was achieved. They should be helped to draw parallels between what they have experienced and actual situations in the world.

### **Pictures: photographs, cartoons, drawing, collage**

"A picture says a thousand words". Visual images are powerful tools both for providing information and for stimulating interest. Remember also that drawing is an important means of self-expression and communication, not only for those whose preferred thinking style is visual but also for those who are not strong in expressing themselves verbally. This tool can be very useful in a peer-to-peer setting.

## GENERAL TIPS FOR RUNNING EVENTS

Events rarely go exactly the way you expect them to. That can be both the reward and the challenge. You have to be responsive to what is happening and to think on your feet. The main things to remember are: set clear goals and be prepared.

### Co-facilitating

If at all possible, always facilitate together with someone else. Teachers will recognise this as “team teaching”. There are practical advantages in that there will then be two people to share the responsibility of helping with small-group work or dealing with individual needs. When two people run a session, it is easier to alter the pace and rhythm to maintain interest. Two facilitators can support each other if things do not go as planned and it is also more rewarding to review together with someone else rather than to do it alone. Co-facilitating requires both facilitators to prepare the activity together and for each to be sure of their role. It is better still to develop activities in a team, preferably involving somebody representing those for whom the activity is meant, e.g. person with inhibitors, a parent, a caregiver.

### Preparing carefully

Make sure that you have read through all the information about the event or session! Run through it in your thoughts and try to imagine how it will go. Try to imagine how the group will react and what they will say. They will inevitably ask questions to which you don't know the answers. These situations happen all the time. Nonetheless, you should make sure that you are reasonably well informed by reading the background information.

### Managing time

Plan carefully and try not to pack too much into the time available. If the session or the day you have planned is taking longer than you anticipated, you will have to try to shorten it if it is not leaving enough time for questions and discussion. It is important to plan adequate time for questions, especially regarding the topics that are new to the community. On the other hand, if you have lots of time in hand, do not try to drag the discussion out, you can either have a longer break or move the other activities up. It often happens that, with the following sessions, the timing evens out again.

### Creating a safe environment

Having in mind that PWI and their caregivers face a number of psychosocial challenges, it is important to create an environment where they would feel safe to participate and share their challenges. Part of ensuring the safe environment is ensuring that all the physical (including the mobility) needs of participants are met and they do not need to feel burdensome when asking for something.

Do not use jargon or language that participants do not understand. People feel safe when they know what is going on, so it is important that they understand what is going on and what instructions they need to follow. No one should feel under pressure to say anything they do not feel comfortable with. It is important to explain the safe environment setting to the participants and community and to review it from time to time, especially when new people join the group.

## Giving clear instructions

Always make sure everyone has understood the instructions and knows what they have to do. It helps to start by explaining in general terms what the activity is about and what it involves, for instance that the activity is a role play. Let people know how long they have to complete a given task and give them a five-minute warning when the time is nearly up so that they can round off.

## Facilitating discussions

Discussion and having one's questions answered is very important. Pay special attention to ensure that everyone who has a question or wants to share a view is given an opportunity to do so. It is also very important that the questions are asked in a way that the rest of the group hear them as well and thus can benefit in full from the answers. This especially applies to themes related to the treatment and management of inhibitors. Without doubt there will be other participants who have the same question, but are shy to ask.

Sometimes discussions "get stuck". This could, for example, be because the topic has been exhausted or that it is too emotional. The discussion can then be prompted with a question, or you could change the course of discussion, or move on.

## Feedback, evaluation and debriefing

Feedback is a comment on something someone has said or done. Too often, feedback is received as negative criticism even though this was not the intention of the speaker. When giving feedback, it is important to respect the other person, to focus on what they said or did and to give reasons for your point of view. It is your role as facilitator to find ways of ensuring that people give feedback in a supportive way.

For example, by:

- ensuring that people start giving the feedback with a positive statement,
- respecting the other person and not making any derogatory remarks,
- focusing on the behaviour, not on the person,
- giving a reason for what they are saying,
- taking responsibility for what they say by using "I- messages".

Receiving feedback is hard, especially when there is disagreement. Your role is to help your participants learn from their experiences and to help them feel supported and not put down. Encourage people to listen carefully to the feedback without immediately defending themselves or their position.

Without reflection, people do not learn much from their experiences. It is essential to include enough time for evaluation and debriefing in your programme. It will also help you to identify your further path and highlight the experiences/ practices that you would not want to repeat in future events. It can be done through an interactive method or a simple discussion, as well as documented in a written evaluation form.

## MANAGING CONFLICT (IN THE GROUP)

In an environment where issues that concern peoples' health, well-being and quality of life are at stake, and often in a situation of very limited resources, it is not unusual for conflicts to arise. The fact that haemophilia and other bleeding disorders are a life-long condition, and that usually the same people cross paths for many years, can lead to differences of opinion or even a simple misunderstanding that, if not resolved properly and in a timely manner, can escalate into an unresolvable conflict.

It is the role of the NMO leadership to spot conflicts early and to facilitate their resolution in a peaceful and timely manner.

### **Conflict can be helpful and creative if managed properly!**

Disagreements and emotions are unavoidable when addressing issues that affect people very personally. Conflicts are difficult to anticipate and may be hard to resolve especially if they arise because participants feel insecure dealing with questions related to emotions and values or if they have totally different approaches to the issue or different values. Try to stay calm and do not become involved in conflicts between individuals in the group.

### **Some tips to resolving the conflict in group**

- Take enough time for debriefing and discussion. If necessary, make more time.
- Help to clarify peoples' positions, opinions and interests.
- Ease tensions in the group. For example, ask everyone to sit down or to talk for three minutes in small subgroups or say something to put the situation into perspective.
- Encourage everybody to listen actively to each other.
- Stress what unites people rather than what separates them.
- Search for consensus. Get people to look at their common interests rather than trying to compromise and move from their stated positions.
- Look for solutions which may resolve the problem without "recreating" the conflict.
- Offer to talk to those involved privately at another time.

If more serious and deeper conflicts arise, it may be necessary to look for an appropriate opportunity to tackle the problem. In the meantime, you could consider how to address the conflict from another angle. Furthermore, by postponing an attempt to resolve the conflict you leave time for those involved to reflect on the situation and to come up with new approaches or solutions.

Having in mind the possibility of conflicts arising, the NMO leadership can already lay the groundwork by ensuring that there are mechanisms in place that prevent some form of conflicts in the more sensitive areas.

## Recommendations for interpersonal conflict prevention

**Ensure that the objectives and ways of working of the NMO are clear to everybody.** Generally speaking, conflicts occur because of differences over facts, goals, methods or values. By ensuring that everybody is on the same page regarding objectives, priorities and plans, you will decrease the chances that dysfunctional conflict will occur due to differences over facts, goals or methods.

**Help people in your community (staff and volunteers) develop positive work relationships.** Give people a chance to get to know each other better personally and to feel more comfortable with each other. This can be done by providing opportunities for social interaction on a continuous basis, by giving assignments that put people into contact with those they do not normally interact with. Team-building activities can be a good option for achieving this.

**Identify a person dedicated to supporting volunteers** who are involved in planning and implementing the activities in the NMO, so that there is a concrete and easily identifiable channel of communication.

**Treat everybody fairly.** Even the appearance of preferential behaviour can create conflict situations. Put in place a conflict management strategy within the organisation, as well as, if and when possible, provide training on communication skills and conflict resolution to the volunteers in your community and staff members, if you have any.



# CHAPTER 5



## EMPOWERMENT AND SELF-ADVOCACY

## INCLUSION OF PWI IN NMO STRUCTURES

People with inhibitors (PWI) are a small minority within the broader bleeding disorders community and have for many years been an underserved minority. NMOs face many challenges to provide services and support to a broad spectrum of bleeding disorders and quite often they do not have the resources or the knowledge to adequately deal with the needs of PWI. Therefore, it is extremely important that PWI take the responsibility to be involved in their NMO, preferably at board level where they can influence the actions of the NMO and help direct the support they need.

### Organisational provisions

In order to achieve the better inclusion of PWI in the NMO several steps can be taken on an organisational level.

As a first step the NMO should **identify** as many PWI as possible in its membership, as well as in the country itself, and make sure that the PWI are present at a variety of relevant meetings of the NMO. This may mean that relevant provisions are put in place, such as special accommodation and travel arrangements. The NMOs need to be aware, however, that PWI might cancel unexpectedly due to a bleed, or choose only a few events to attend due to the tiring nature of participation in meetings. Nevertheless, the opportunity to participate should be offered on a regular basis.

In addition, each NMO should have a **multi-annual action plan** in place that contains provisions for including PWI at a meaningful level in the NMO among other things. Ideally, this kind of plan should be made in consultation with the PWI. If the NMO is aware of PWI who can contribute they should approach those PWI and ask them to participate in the NMO. If the NMO is not aware of such PWI then an appeal to the members asking them to nominate such a person can be helpful.

Furthermore, the appointment of an **Inhibitor Ambassador** to liaise with the European Inhibitor Network can be a helpful step for PWI inclusion in the NMO. On one hand, it would establish a direct link between the NMO and the EIN and, on the other, - serve as a tool to empower PWI and initiate a sense of ownership over their own programmes within the NMO.

### Active inclusion, training and empowerment of PWI

To further strengthen the engagement of PWI, the NMO will need to take further a number of steps, namely actively include, train and empower PWI.

Setting aside a special time to introduce PWI with the materials on inhibitors and inhibitor management available from the NMO as well as online (please see **Useful links** page of this handbook) can be a good starting point.

As indicated above, the participation of PWI in various meetings and events of the NMO should be facilitated. It can be helpful to evaluate those meetings and events (especially the practical arrangements) together with the PWI that have attended, to further improve them.

In addition, the European Haemophilia Consortium (EHC) has in place a number of events such as the Leadership Conference and Youth Leadership Workshop, which are designed to train and promote future leaders of the NMOs and encourage self-advocacy and empowerment. The EIN holds a workshop on empowerment and advocacy specifically dedicated to PWI each year prior to the EHC Conference. Participation in those events can help the NMOs to educate, inspire and empower their volunteers, as well as to gain new insights and inspiration from the other NMOs. Funding for participation to these events is available from the EHC and ideally the NMOs should nominate PWI to attend these training events on a regular basis. It is essential to receive feedback about the experience, conclusions and new ideas from those events from the PWI that have taken part, thus strengthening the link between PWI and their NMO.

Following these steps could help the NMO to establish a base of committed, well trained and passionate group of PWI volunteers to further the work of the NMO in terms of people with inhibitors.

### Acknowledgement of volunteer contributions and impact they are making

Volunteers are the lifeline of all NMOs, the EIN, the EHC and the World Federation of Hemophilia (WFH). The contribution they make is immeasurable, their passion and energy are admirable, but it is essential to establish a mechanism of volunteer management in order to keep the contribution, passion and energy up.

A few keywords to successful volunteer management are:

**Defining roles** – it is essential that the roles and tasks of the volunteers are clearly defined – Who does what? Who reports to whom? Who carries the final responsibility?

It is also important to assign people tasks that are suitable for them in terms of capabilities, skills and interests, as well as their physical condition. The volunteers should know that they are making a meaningful contribution and their efforts are making an impact.

**Training, monitoring and support** – it is critical to familiarise and train the volunteers on the tasks they will be doing and projects they will be working on, as well as the organisation (they may not always know how exactly the NMO works). In addition, it is necessary to ask what kind of support and how regularly they will need it, as well as how they will be monitored by weekly, monthly or quarterly meetings?

**Enjoyment** – people mainly volunteer in their free time and with all the pressures of life, we all want to spend our increasingly precious free time enjoying ourselves. Therefore, making volunteering enjoyable is critical as we are competing with the other things that they could do in their free time – going to the cinema, having a meal with friends, etc. This can be a meal together after a weekend of events, an excursion somewhere or a volunteer event at the end of the year. This all makes volunteering rewarding.

**Evaluation, recognition and gratitude** – to know that the volunteers are happy doing what they do, it is important to **evaluate regularly**. This will help the NMO to adapt and improve their strategy in terms of volunteers, as well as to provide people with feedback about their performance. At the same time, it is essential to **acknowledge** the volunteer contribution regularly, regardless of how they do. Simple things like a **thank you** or a personalised card once a year lets them know they are appreciated. A formal award for volunteers who give exceptional service is a good idea.

Most important is to include the volunteers in the planning and decision-making process of the NMO by having them represented on the board and participating in all event planning. This way an equal participation in the discussion and shared goals are ensured.

To be prepared in case things do not always go so smoothly, it is crucial to have a conflict management strategy in place.

## EMPOWERMENT ESSENTIALS

The ability of PWI and their caregivers to communicate, educate themselves, take part in social and recreational activities, have diverse and international experiences and/or build a family life significantly contributes to their empowerment and active participation in the life of the NMO. To the extent possible the NMO should encourage all these things through a variety of channels and activities, so that the PWI are empowered and actively engaged.

### J - adult with haemophilia and inhibitor in his 60's.

He shares his story about the way to empowerment and how communication in different contexts is key, along with two quotes from **Dalai Lama**:

*"Just one small positive thought in the morning can change your whole day."*

*"Choose to be optimistic, it feels better."*

### A Lifetime of communication

All babies are born with the ability to communicate naturally. Babies know that if they make noise they will be heard. Different noises mean different things and get different reactions. A cry can mean hunger while a scream can mean pain.

As we grow we need to develop our communication skills and find new ways to engage with others. We learn that words have meaning and saying a certain word will get a certain reaction. We learn to put sentences together. We learn to ask questions and increase our knowledge. Most importantly, we learn to listen to what others are saying and we can then interact with them.

### School and education

Outside of family the first big challenge is learning to adapt to school. Of course, parents have to explain the meaning of being a PWI to school staff and use the support available from the NMO or medical support team to reinforce it. But after that we are on our own in terms of communicating with others at school.

It may be necessary to take a back seat when certain sports are played. But as it is important not to feel different this means looking at options to play in the goal for football or assist the teacher with the selection and management of the team. The important thing is to find a way to participate in all activities while minimising the risk of serious bleeds.

Many other activities at school such as taking part in a quiz, public speaking and debate and drama classes all improve our confidence and ability to self-advocate.



Each time you attend a doctor's visit or meet other medical professional, use the opportunity to learn more about your individual condition and about what is happening in the field of haemophilia and particularly inhibitors. This will develop trust and interest between you and the medical support team and help you to ask for an individual care plan and better support if you need it. Knowledge impresses medical teams.

Understanding your condition better will also help you to explain to your school friends what your condition is and what support you need from them.

## **Recreation**

At all stages in your life it is important to take part in as many activities as you can and to spend time being with people and having friends. By selecting the type of activity you become involved in carefully you can avoid physical contact sports, etc., and concentrate on activities where you can use your knowledge and creativity, and succeed equally with others. Learning about debating and public speaking in competition will serve you well later. It is possible to have a full social life through these activities and be accepted for who you are.

The fluency and comfort you find in speaking to others and participating in meetings and on committees, etc., gives a lot of confidence when dealing with the medical profession and coping with health issues.

## **Work**

There are no limitations today as to the type of work you can apply for. New treatments are making it possible for PWI to participate fully in the workplace and undertake work that was not possible previously.

The world of work opens many doors to opportunity, self-progression and self-achievement.

There are still employers who may be hesitant about taking on a PWI due to lack of knowledge about the condition. It is good advice not to discuss your medical condition at the interview stage. Instead, wait and see if you are offered a contract. At that point you may wish to discuss your medical condition explaining that your treatment regime controls the condition and there are no medical reasons why you cannot do the job successfully. It will be very difficult for an employer to withdraw a contract on the basis of your new medical disclosure.

Many jobs offer the opportunity to travel and this can be a really rewarding experience where you meet new people and develop new social networks. Foreign travel is especially rewarding as you learn to communicate and work with people from different cultures and backgrounds. It builds self-confidence and empowers you to do more at every level in your life. It teaches you how to be very clear and very careful in what you communicate and how you communicate with others.

New treatments make it less likely for you to have a bleed when travelling, but if you do have a bleed, self-treatment is very effective and treatment centres are well equipped and available in most European countries and beyond for more serious bleeds. When abroad, online tools such as Haemophilia Centre locator ([www.hclocator.org](http://www.hclocator.org)) may be helpful in finding the nearest HTC.

## Family and friends

We are nothing without family and developing and keeping good friends makes our lives a whole lot more satisfying and complete.

Living with haemophilia and inhibitors can be a difficult and stressful experience with many challenges along the way. Having somebody with whom to share the difficult times and discuss the problems is very important.

It is an individual decision what to share with a partner and particularly if you wish to involve your children as it might be a distraction from their own lives and careers.

So, the decision about who to communicate with, and how much to communicate, is down to the individual. If you are close to somebody it is possible to discuss everything and, if not, decide how much you want the person to know.

## Travel

It is now possible to travel anywhere in the world and take treatment with you. Travel is a wonderful experience and it opens up a whole new world of adventure. Once you have made a few trips and survived without major incident you become more relaxed and happy to travel for longer and to more distant places.

Only your imagination can limit the type of holiday you can enjoy. I have been lucky enough to experience a Safari, Arctic holidays, cruises and jungle breaks. I recommend you try them all and enjoy the experience.

The most interesting thing when travelling is meeting new people from different cultures and learning a little about their lives and telling them a little about your life. This is a very good way to improve your skill at communicating and getting comfortable with different audiences. Getting involved with the EIN will allow you to make new friends from many countries who have experienced similar issues to you in their lives.

## Retirement

For those who have finished their work life and can enjoy a fruitful retirement it is a time when you can give more voluntary effort to your NMO, the EIN etc. Ask at NMO and EIN level if there is a project you can get involved with and help to give back a little to other PWI.

Communicating your story and listening to others communicating their stories, raises the profile of inhibitors so much that now we are beginning to see new horizons with better treatments and closer cooperation through events like the EHC Inhibitor Summit which gets bigger and better each year.

If there was ever a good advertisement for communicating as an aid to advocacy then surely this is it. Make sure you experience it and ask your NMO to allow you to participate.

Getting old disgracefully means that in retirement we can still have fun and not worry too much about what we say and do.

# USEFUL LINKS AND RESOURCES

## Publications

- *European principles of inhibitor management in patients with haemophilia\**, Giangrande et al. Orphanet Journal of Rare Diseases (2018) 13:66
- *Compass. A Manual on Human Rights Education with Young People*, Council of Europe Publishing, 2002
- *Comprehensive care in hemophilia*, Arlette Ruiz-Sáez (2012), Hematology, 17:sup1, s141-s143
- *Different. Just like you: A psychosocial approach promoting the inclusion of persons with disabilities*, International Federation of Red Cross and Red Crescent Societies Reference Centre for Psychosocial Support, 2015
- *EHC Novel Treatment Products Newsletter*, [www.ehc.eu/novel-treatment-products-newsletter/](http://www.ehc.eu/novel-treatment-products-newsletter/)
- *A randomized trial of factor VIII and neutralizing antibodies in hemophilia A*, Peyvandi F, Mannucci PM, Garagiola I, El-Beshlawy A, Elalafy M, et al., N Engl J Med. 2016;374:2054–64.

\* This publication cites more useful publications in the list of references.

## Useful links

- [www.ehc.eu](http://www.ehc.eu)

## Information about inhibitors:

- [inhibitor.ehc.eu](http://inhibitor.ehc.eu)
- [www.uptodate.com/contents/inhibitors-in-hemophilia-mechanisms-prevalence-diagnosis-and-eradication](http://www.uptodate.com/contents/inhibitors-in-hemophilia-mechanisms-prevalence-diagnosis-and-eradication)
- <https://www.hemophilia.org/Bleeding-Disorders/Inhibitors-Other-Complications/Inhibitors-for-Consumers/What-is-an-Inhibitor>
- <https://www.hemophilia.ca/inhibitors/>
- <https://www.wfh.org/en/page.aspx?pid=649>

## Assistive devices:

- <https://www.nichd.nih.gov/health/topics/rehabtech/conditioninfo/device#f4>

All the links can be found and clicked on **[inhibitor.ehc.eu/resources/handbook](http://inhibitor.ehc.eu/resources/handbook)**

## **European Principles of Inhibitor Management**

1. Awareness of the incidence of inhibitors and risk factors throughout life
2. Early recognition and accurate diagnosis
3. Optimal organization of care and communication between all stakeholders
4. Access to haemostatic agents
5. Inhibitor eradication by immune tolerance induction (ITI) therapy
6. Access to, and optimal preparation for, surgery and other invasive procedures
7. Provision of specialist nursing care
8. Provision of tailored physiotherapy care and monitoring
9. Access to psychosocial support
10. Involvement in research and innovation