

# Caring for people with inherited bleeding disorders

## Information for staff working in residential care facilities

With improved treatments, people with inherited bleeding disorders such as haemophilia are now living longer than ever before. More people with bleeding disorders are ageing and may need supported care in a residential aged care facility.

### What are bleeding disorders?

Bleeding disorders are health conditions where blood doesn't clot properly and healing takes longer to occur. They are caused when blood does not have enough clotting factor. A clotting factor is a protein in blood that controls bleeding. They include:

- haemophilia A
- haemophilia B
- von Willebrand disease
- and other rare bleeding disorders.

Bleeding disorders can be inherited or acquired. Inherited disorders are passed down from parent to child through genetics while acquired disorders can develop or spontaneously occur later in life. These disorders affect both men and women, although men are more likely to have haemophilia.

### Bleeding disorders are not contagious.

The main problem for people with bleeding disorders is internal bleeding episodes into their joints and muscles, causing pain, swelling and bruising. They bleed longer than other people, but not faster. Their treatment, which is usually clotting factor replacement therapy, helps to control their bleeding.

Please note that when it comes to any surgery, medical or dental procedures, or injury **ALL** residents with an inherited bleeding disorder must be reviewed by their Haemophilia Treatment Centre (HTC) and may need extra treatment or other interventions. Aged Care facility staff should inform the HTC as soon as they are aware of any upcoming invasive procedures.

Many older people with bleeding disorders grew up without adequate treatment because there was not enough treatment product available at the time. They may now have arthritis and severe joint problems in their elbows, ankles, knees, etc.

- Their help and advice on lifting and transferring them will be very useful – they will know best how not to make the pain worse and how to avoid knocks and bruises on equipment.
- Remember to protect the resident's skin and joints when using equipment to avoid skin tears, bruising or joint injuries.

Most people with bleeding disorders manage their condition well and are very independent. Being respectful of their knowledge and sensitive to their past experiences will help them to settle in to residential care.

- Most will have spent many years injecting themselves with their factor treatment, or their partner or carer may have been giving them their treatment and will know what works best for them
- They have been encouraged by their specialist haemophilia health care team to be involved in their medical care and treatments. It would be valuable to continue to involve the resident and/or carer in decisions on managing their disorder.

Some residents with inherited bleeding disorders may have received contaminated blood products in the past and as a result were infected with HIV, hepatitis B and/or hepatitis C.

- Not all of these people have told friends and family about their HIV or hepatitis B or C. Confidentiality is extremely important. Only staff involved in clinical care need to be aware if a resident has a blood borne virus.
- Bear in mind that, even if their medical record shows exposure to hepatitis C, nearly all of those who had hepatitis C in the past will now have had successful treatment and been cured.
- Some residents will feel comfortable in discussing their HIV or hepatitis B or C, but some may not. Please be sensitive towards residents' feelings as some may have had a lifetime of hardship related to their blood borne virus and it may have had a big impact on them.

## Management after an injury

Please refer to the resident's HTC Treatment Plan for specific information about the management plan for your resident in your facility.

If a resident is injured, the clinical staff should always assess them immediately. **Never keep them waiting.** A resident can feel a bleed before there are any obvious signs or symptoms. Treatment should be a priority if there is suspicion of injury.

### Residents will require urgent medical assessment and management of their bleeding disorder if they have:

- Any fall or injury in which there is trauma to the head, eye, throat, chest, back, abdomen, hip or groin
- Broken bone (or are suspected of a broken bone)
- Cut requiring sutures/stitches
- Common bleeds from the mouth, nose, cuts and scrapes that do not stop bleeding after 20 minutes of general first aid

### Signs and symptoms of a bleed:

- Complaints of pain, tingling, bubbling, filling sensation in a muscle or joint, stiffness or decreased range of movement (ROM) in a leg or arm
- Swollen body part or an area, joint or muscle that is warm to touch
- Favours an arm or leg more than usual
- Resident limps or refuses to use leg or arm.

### Use first aid guidelines and standard precautions:

- Wash hands, wear gloves
- Keep wound clean
- Clean blood spills
- If factor replacement therapy is used, dispose of needle as per facility policy