# patient preferences in haemophilia

Recent research in patients with haemophilia A and their caregivers has shown that there are some important factors to understand when making decisions around their treatment

These include efficacy, safety and the possibilities for personalisation, all of which are important to achieve protection against bleeds and to live life beyond haemophilia<sup>1-5</sup>

You may ask yourself a few questions when thinking about treatment for you or a loved one:

### Does it work?

Will I

be safe?

Efficacy means how well a treatment prevents bleeds

Data relating to efficacy and safety are collected for individual treatments around the world, both during and after clinical trials

about the safety and efficacy of the different treatment options provided to you Safety relates to the side

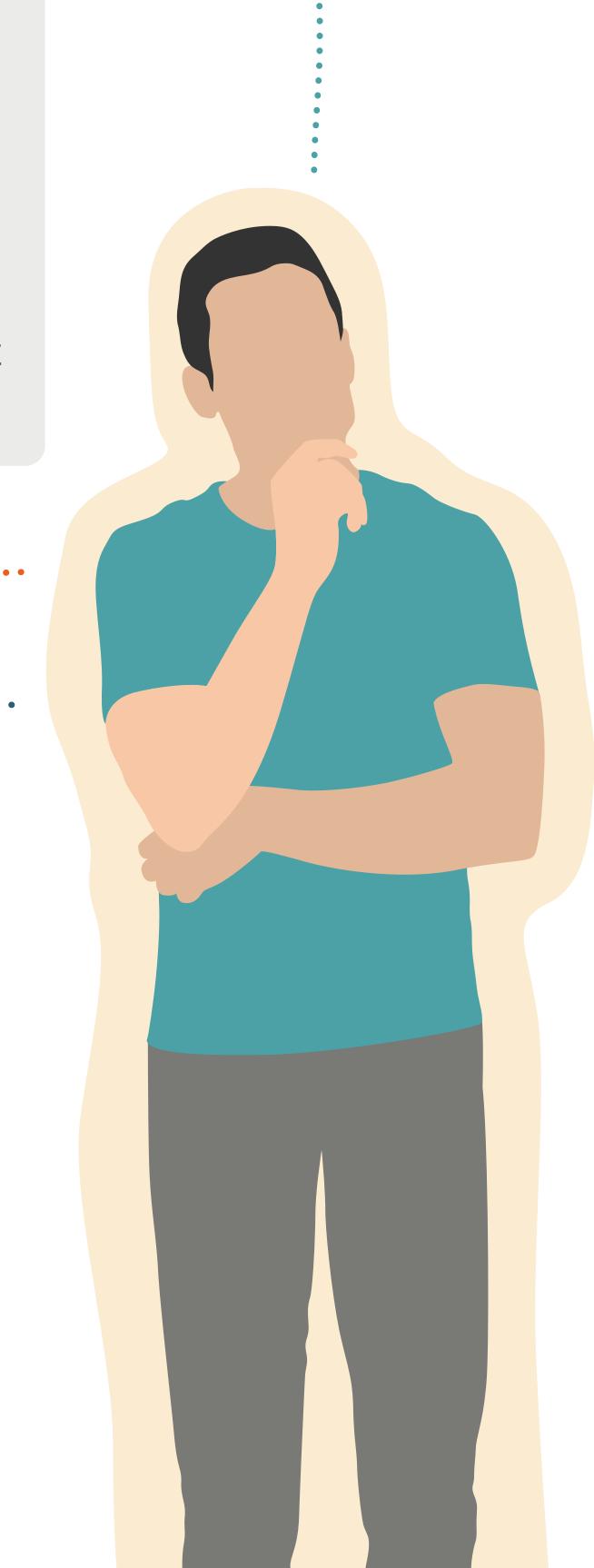
You can ask your doctor for information

effects that may be associated with a treatment How can it work for me?

### **Personalisation** relates to ensuring a treatment suits you as an individual.

This might include: Considering your lifestyle and aspirations, both for now and as these change for the future, and how your treatment can help in achieving these

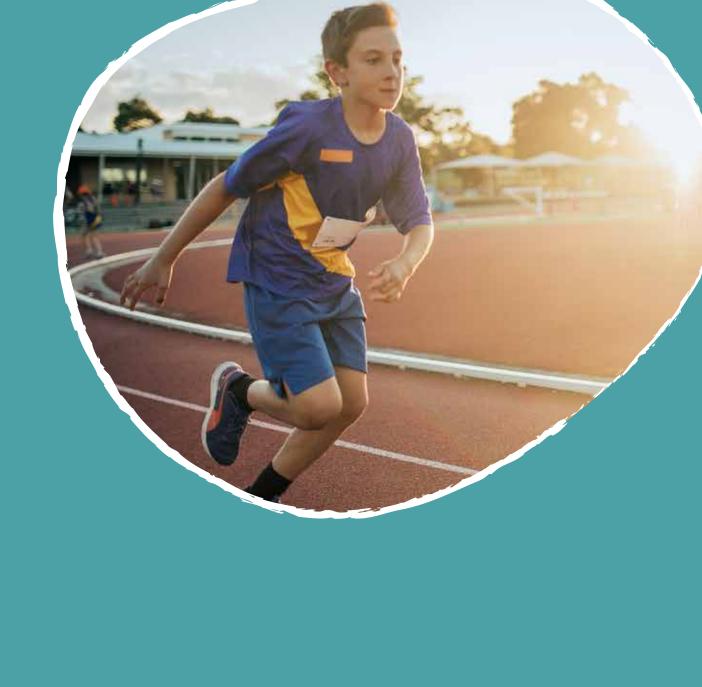
- Ensuring that you have the right level of protection to live your life as you wish, which might include playing sport, taking part in activities at school,
- or keeping up with your friends and family Being able to plan treatment to fit in with daily life, rather than the other way around



## different priorities for their treatment Here are some examples of the diverse lifestyles that patients lead and the considerations they have

People with haemophilia A have varied lifestyles and so have

taken when thinking about their own treatment



#### damage to my joints when I was playing sport at

James, 11 years of age

school. My doctor helped me choose a treatment regimen that works for me, and we planned my treatment to make sure I have a higher level of protection on the days when I play sport. I am glad that this change has helped me to take part in more activities with my friends; this is really important to me

I used to be scared of hurting myself and causing



I like to keep active throughout the week, how can I personalise my treatment to my lifestyle?

How can I make sure I can join in with activities at school

Jon, 25 years of age

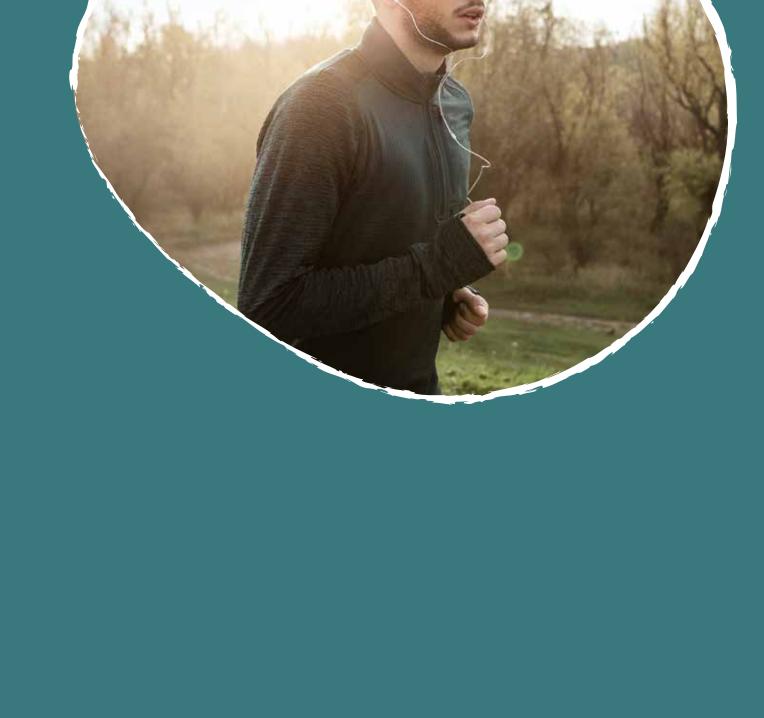
without my haemophilia holding me back?

#### a lot for my job. It took a while for me to realise that I could (and should!) tailor my treatment to suit my

to take my medication and I just hoped for the best. I just needed to talk to my doctor about how I could personalise my treatment to ensure I was protected, whilst also allowing me to do my job. Even though I can't travel at the moment, I have kept on top of my treatment to ensure that I am protected for other activities – I go indoor rock climbing on Tuesdays and play tennis on Fridays, so I need higher protection on those days. My treatment schedule suits me as I can lead the active life that I enjoy My schedule changes every week, is there an app available that could help me plan my treatment accordingly?

Before the COVID-19 pandemic struck, I used to travel

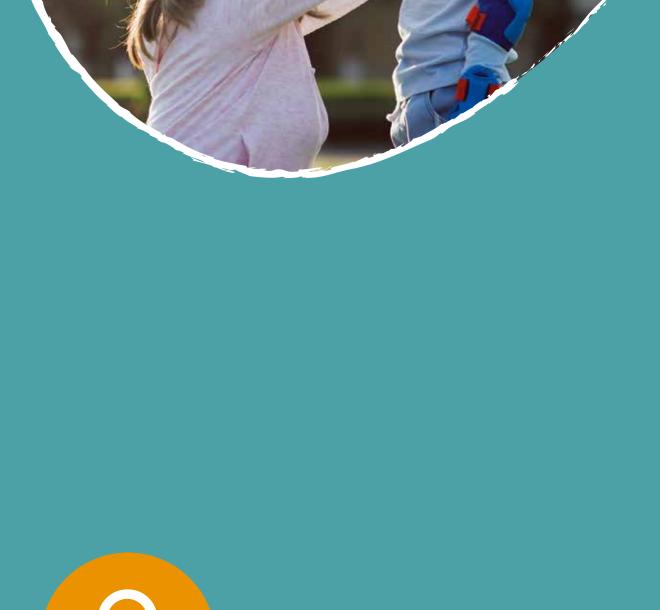
lifestyle – before, I was not very good at remembering





4 years of age

What should I do if I forget to take my treatment?



#### important too. Keeping active also has benefits for his confidence and social skills; he loves playing in the park with his friends and we often go on family bike

rides at the weekends. I feel better knowing that there

are medications to help manage the risk of bleeds that

exercise can bring, whilst allowing him to keep healthy

I do worry that my son will injure himself and cause a

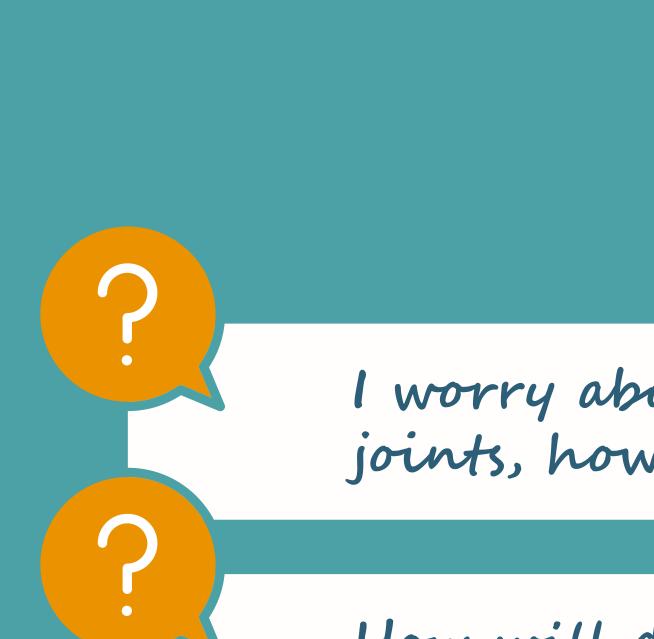
joint bleed, but I also know that keeping physically fit

and having well-developed muscles as he grows up

will help keep his joints healthy, which is really

Katherina, caregiver to son Sebastian,

and active I worry about my son hurting himself and damaging his joints, how can I ensure that this does not happen? How will decisions I make about my son's treatment today



affect his future?

#### Other than walking to the local shop each day with my dog, I am not very active, but I do keep very busy! I

As I get older, how can I ensure that my treatment provides me

David, 65 years of age

Michael, 30 years of age

have just retired and am really enjoying spending my

friends and family. I can easily fit in treatment around

my hobbies, which is really important to me

time reading, painting, and spending quality time with





## active Grandfather too!

I am not sporty, but I want to be sure that I am always

How can I plan my treatment schedule to fit in with my family life? Greg, 70 years of age

once caused a bleed just by picking up one of my

my treatment allows me to achieve a good level of

children. With my doctor's help, I have made sure that

protection whilst also fitting into my weekly activities.

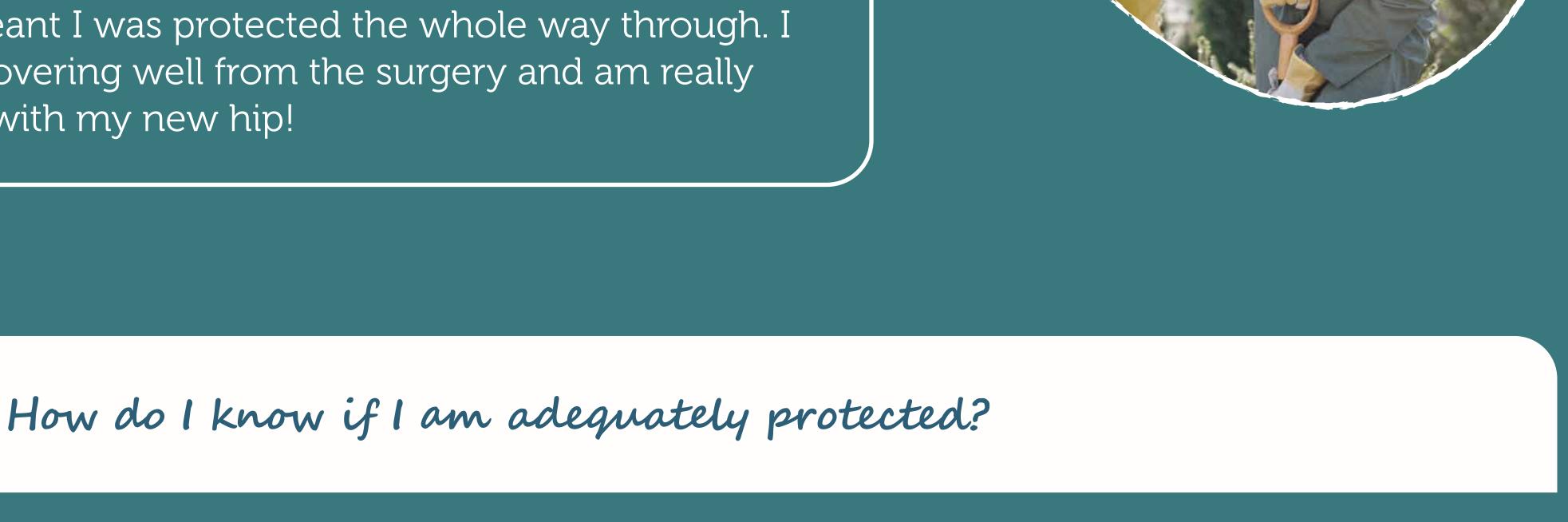
It's important to me that I am able to continue being

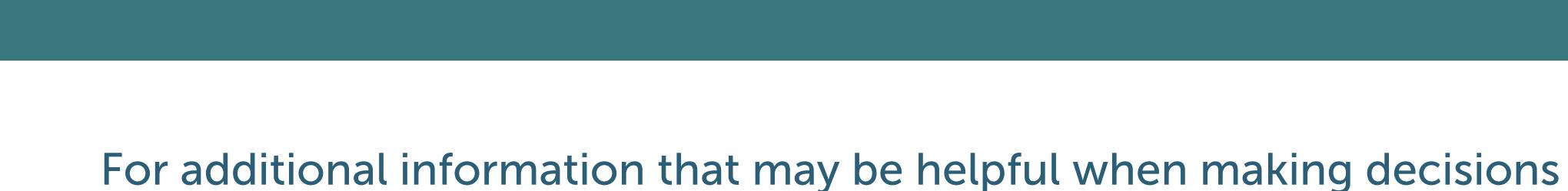
an active Dad to my children and maybe, in time, an



about what this meant with my haemophilia A. My doctor talked me through the options, and we made a plan for treatment before, during, and after surgery that meant I was protected the whole way through. I am recovering well from the surgery and am really happy with my new hip!

protected, how can I achieve this?





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