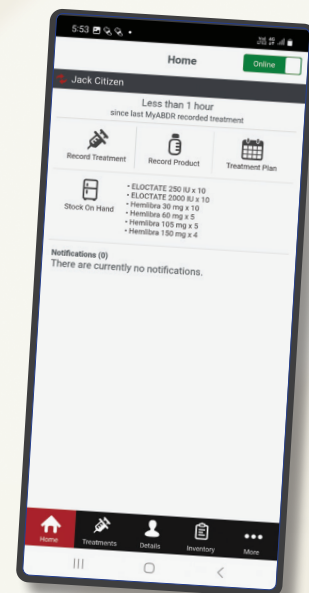


MyABDR and recording your treatment

Suzanne O'Callaghan



With new haemophilia treatments now available and more in the pipeline, recording treatment and bleeds in MyABDR is more important than ever. Although people's treatment experience has improved remarkably, the treatments have had unexpected results - ironically being more challenging for remembering to treat and record and managing treatment delivery.

WHAT HAS CHANGED?

For people with haemophilia, the effect of the new treatments generally lasts longer so they don't need treatment infusions as often and are experiencing fewer bleeds. You will have seen recent Congress reports that Haemophilia Treatment Centres (HTCs) are seeing how this impacts on adherence to treatment, for example, patients forgetting when to have their prophylaxis or to record.

HTCs also have to keep track of treatment product orders. Their patients don't require as many vials and in some cases treatment delivery methods have changed, for example, with emicizumab (Hemlibra®), from home delivery to picking it up at the community pharmacy.

WHAT'S THE VALUE OF MYABDR?

The MyABDR app was developed as a tool for patients and parents to enable people with bleeding disorders and their (HTC) to monitor and review their treatment and bleeds. It links directly to the Australian Bleeding Disorders Registry (ABDR), the system used nationally by HTCs for the clinical care of their patients. There is an app for mobile devices and a website version, with graphs and other reports on treatments and bleeds.

What can you do with MyABDR?

- Record treatments and bleeds as they occur – and add notes or upload photos
- Manage stock of treatment product (at your fingertips when you get the call asking what stock you need)

- Share and discuss the information with your HTC
- Have accurate records of your treatments and bleeds to look over anytime and discuss at your review – rather than trying to remember what happened
- Update your contact and personal details.

HTCs use the ABDR to monitor treatment outcomes for their individual patients but at a broader level they are also collecting 'real-world' data to measure the impact of the new treatments across their patient population. The ABDR and MyABDR have highlighted these issues with the new treatments.

HTCs are very aware of the challenges facing their patients.

Julia Ekert, Haemophilia Data/Product Manager at the Royal Children's Hospital Melbourne, suggested that people **use MyABDR functions as a memory prompt.**

'MyABDR works as a really good recording tool to remind you when you need to do your next dose. These days, when you're giving yourself or your child treatment less frequently, it can be hard to remember.'

'And it helps the HTC to know when your next script is due, if we know what you have at home and where you are up to.'

Participating in research studies is an important way to be part of the development of new treatments. If you are interested in clinical trials, having a **proven track record of treatment recording can work in your favour**, commented Megan Walsh, Clinical Nurse Consultant at the HTC at The Alfred in Melbourne.

'Clinical trials all require accurate record keeping and they usually check the past usage records as well.'

RECORDING TIPS

Everyone has their own preferences for ways of remembering to record stock or treatments in MyABDR – but sometimes it can help to find out what other people do. We asked our HFA MyABDR Focus Group for their tips.

Recording treatments

Many make a practice of **recording their treatment in MyABDR when they have it.**

‘The only way I am sure to record the receipt of Hemlibra® or factor and infusions is if I do it on the day.’

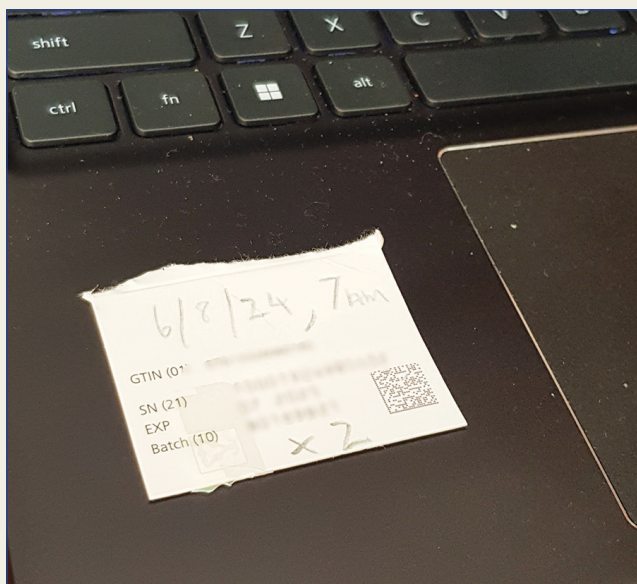
‘Get into the habit of bringing your device with you when injecting so it’s right there and you don’t forget.’

‘If I log in to the MyABDR app towards the end of having a routine prophylactic treatment, then the date and time are autofilled. And all other details are clear in my mind.’

‘Put the app on your device’s front screen so it’s always in sight. Even subconsciously you will see it and this helps to remind you to use it.’

‘I have my electronic calendar set up with a weekly recurring Hemlibra event on my designated treatment day. Email reminders work better for me than phone notifications.’

What if you are **too busy to record at the time** or it’s not convenient?



‘I rip the top off one of the boxes, attach a sticker from a vial and write the date on it. Then when I have entered it into MyABDR, I put a line through it. Easiest way to tell if I’ve put it in the system.’

‘I sometimes tear off the panel of the cardboard box that has the batch and expiry. I scribble the ‘time and date of use’ on it, so that I can make the MyABDR entry later, when I’m not in a rush. I leave it in a prominent place, near my computer or on the bench where I can’t miss it.’

‘I have old treatment recording sheets onto which I place the stickers from my product vials. I keep the paper record with my treatment kit and fill it out before packing up. Then when I come to enter data into MyABDR, it’s all in one place.’

‘I use the web version of MyABDR to record my doses and update my inventory. I do this when I am sitting at my laptop catching up on emails. Sometimes I ‘snooze’ the reminder email, so that it returns to the top of my inbox.’

What about tricks for recording your treatment stock?

‘After I collect my Hemlibra from the pharmacy, I take a picture of the whole lot, batch/expiry panels face-up, on my phone. It uploads to the cloud automatically, so the info is available on my laptop when needed. The date is automatically recorded.’

With more long-acting and highly effective treatments in the pipeline, remembering to treat and record is going to be an ongoing issue. Developing easy strategies to manage it will be crucial. Do you have strategies to share? Email Suzanne at HFA with your tips – socallaghan@haemophilia.org.au.

FIND OUT MORE ABOUT MYABDR

including MyABDR support contact details:

www.haemophilia.org.au/myabdr

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Suzanne O’Callaghan is HFA Policy Research and Education Manager
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