

This Treatment Diary belongs to:

Your Name

TREATMENT DIARY





Available now on iPhone, Android phones and the web.

Download the app now from the Apple App Store or Google Play.

Or go to www.blood.gov.au/myabdr



What is MyABDR?

MyABDR is an electronic version of this Treatment Diary and offers so much more. It gives you a quick, easy and secure way to:

- View reports and graph your information
- Automatically share your treatments and bleeds with your Haemophilia Centre
- Record notes about your condition and treatments
- Manage your stock of treatment products
- Update your contact and personal details



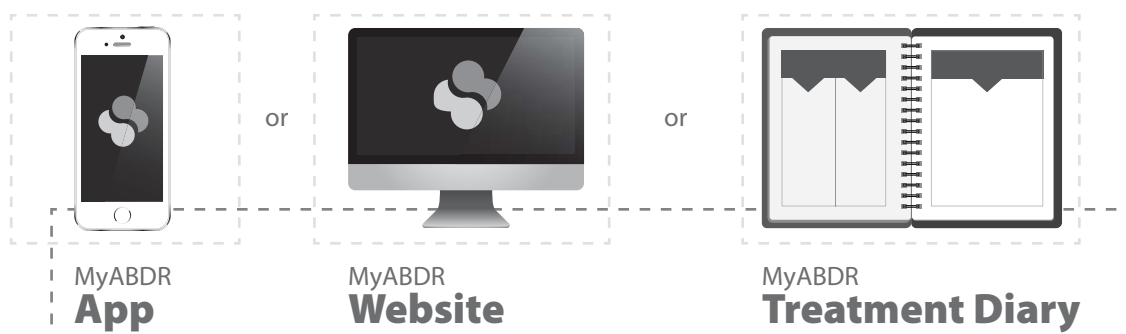
Why is it so important for me to keep records of my treatment?

Your treatment records are used by your Haemophilia Centre to make sure the treatment plan they set out for you suits your individual circumstances. The information also helps doctors treating bleeding disorders across Australia to understand trends and patterns with treatment which is very important for rare conditions such as haemophilia and von Willebrand disease.

Statistical information is also crucial to governments to purchase clotting factor products and understand demand for them into the future.

Where do I need to record my treatments?

You have the option to record your treatments using the:

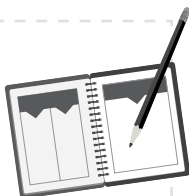




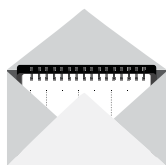
What do I do when my MyABDR treatment diary is complete?

It is important for you to discuss your record keeping practices with your Haemophilia Centre. They will advise you to either:

Bring completed diaries with you to your next clinic appointment.



or



Make arrangements for you to return completed diaries by post.

The diary is designed so that the information can be entered into and attached to your Australian Bleeding Disorders Registry record. Discuss how your records will be managed with your Haemophilia Centre.

Where do I get more copies of the MyABDR diary?

Contact your Haemophilia Centre for more copies. See the back cover of this diary for contact details.

Alternatively you can call 13 000 BLOOD (13 000 25663) or email myabdr@blood.gov.au to request additional copies.



Example of a completed entry

STEP-1: Record the day, date, time, treatment type, product and batch details including any notes, for each treatment, as shown in the example below. If the Treatment Type is "Bleed" also complete Step 2; if treatment is for "Surgery/Procedure", include a date and description in the Notes field for the first treatment - all follow-up treatments for the "Surgery/Procedure" will be associated to the first entry.

Day	Date	Time	Treatment Type	Product and Batch (vial size x Number)	Stick Labels here
Monday	04.01.2014	8:15 AM	B	Kogenate 1000x2 27ON6W1	

Write the letters that corresponds to your **Treatment Type** here:
P-Routine Prophylaxis
B-Bleed
Pr-Preventative
TP-Temporary Prophylaxis
SP-Surgery/Procedure
ITT-Immune Tolerance Therapy
O-Other (specify)

Write in size, number of vials and batch number OR add label/s

STEP-2: Record Bleed details the first time "Bleed" is treated, then write the "Bleed Date" in "Notes" for each follow-up "Bleed" Treatment.

Bleed details	Bleed Date	Part of Body	Reason#	Severity of Bleed+	Time to Treatment -
	04.01.2014	left knee	Fa	2	G
Notes (Include Surgery date and description if Treatment Type = Surgery/Procedure) <i>injured in fall at school</i>					

Record **Part of Body**, note Left or Right or both when necessary, e.g. Left Knee or Both Ankles.

Write in the letters for **Reason#**
AT-Accident/Trauma
Fa-Fall
Fr-Fracture
Post-PostSurgery/Procedure
Pre-Presurgery/Procedure
P-Procedure
SI-Sporting Injury
U-Unknown (Spontaneous)
O-Other

Write in the number for **Severity of Bleed+**
1-Minor
2-Moderate
3-Major

Write in the letter for the **Time to Treatment:**
I-Immediately
W-Within 3 Hours
G-Greater than 3 Hours

Make notes about your treatment and bleeds here. If it was for Surgery/Procedure, include the planned date for your surgery/ procedure and a description the first time you treat for it.



Definitions

► Treatment Type

Routine Prophylaxis: Your regular treatment to prevent 'spontaneous' bleeds occurring (you may also refer to this as prophylaxis)

Bleed: Treatment for a bleed, including follow-up treatments (you may also refer to this as 'On Demand')

Preventative: Treatment before activity to prevent bleeds (may be used in conjunction with prophylaxis)

Temporary Prophylaxis: Short-term regular treatment to manage a specific bleed or joint problem

Surgery/Procedure: Treatments before, during and after surgery or a medical/dental procedure

Immune Tolerance Therapy: Treatment for inhibitors involving frequent doses of factor concentrates over a long time in an attempt to train the body to recognise the treatment product

Other: Treatments for other reasons

► Severity of Bleed

Minor: Bleed is barely noticeable. It does not make you uncomfortable or have any effect on what you normally do during the day or how you do it.

Moderate: Bleed makes you uncomfortable. It affects how you do the things you routinely do every day.

Major: Bleed is very painful or uncomfortable. It stops you from doing normal daily activities. It may keep you awake when you are trying to sleep. You may need to go to hospital for treatment or review.



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Treating Bleeds

Factor: should be administered as soon as possible and bleeds should be reported to your Haemophilia Centre. Always seek additional medical advice if there are continued symptoms of pain, swelling and restricted range of movements within the joint or muscle.

Why?

Reporting bleeds to your Haemophilia Centre allows your health care team to identify serious bleeds or cumulative bleeds that may be target joints. With the advances in factor replacement, correct rehabilitation is sometimes overlooked. RICE is vital in the management of joint and muscle bleeds.

Rest: a decrease in activity is encouraged for at least 48 hours after a bleed. If the bleed is in the lower limb, crutches should be used with non weight bearing through the limb. Your physiotherapist may use additional splinting or casting to provide support to the joint or muscle and will provide a guide to continued use of crutches and transition back to weight bearing over suitable time according to symptoms. The general rule of thumb is you need to be on crutches until full, pain-FREE range of movement is achieved.

Why?

Factor replacement stops the bleeding, but it does not heal tissue. Rest allows the TIME needed to achieve healing of the damaged tissues be factored in to your treatment regimen. This helps stop rebleeding (including small micro-bleeds that can be undetected) from occurring and also ensures that a joint is less likely to have permanent damage. There is evidence to show that walking on or using a blood filled joint can severely increase damage to cartilage.

Ice: cold in the form of crushed ice, frozen peas or cold packs can be applied to the local area. The chosen product should be wrapped in a cloth to prevent ice burns. There is evidence that cold therapy can assist with a reduction in pain and it is thought that it may lessen localised swelling. It should be applied for no longer than 15-20 minutes and can be repeated second hourly as tolerated.

Why?

Ice is well established in aiding pain management, although current thinking is that factor replacement should be administered first.



Compression: a supportive bandage/tubigrip can provide additional support to the area. Your physiotherapist can provide you with the best options. Bandage/tubigrip should be removed at night.

Why?

Compression can stop the amount of swelling and blood present at the site of the bleed. This may prevent further muscle and other soft tissue damage and can reduce how much blood has to be reabsorbed in the joint or muscle.

Elevation: part of body should be above the heart if possible; if in the leg should at least be above the groin.

Why?

Elevation uses the principal of gravity to allow drainage from the area of the bleed to lymph nodes in areas such as the groin and underarms where swelling is most effectively absorbed. In combination with Factor, Rest, Ice and Compression it can reduce the bleeding and swelling, and speed up recovery.

Source: Australian and New Zealand Physiotherapy Haemophilia Group

Important note:

- General information, not intended as medical advice.
- Consult your Haemophilia Centre or health care team for all treatment related matters.

Are you having a bleed...??

STEPS

- ✓ Factor Now
- ✓ Start R.I.C.E Regime
- ✓ Report Bleed

FACTOR ALONE **DOES NOT EQUAL TREATMENT**

Physiotherapy means a speedy recovery
& a safe return to activities.

TO RECOVER QUICKLY FROM *bleed*, OR JUST SPRAINS OR STRAINS

R.I.C.E

Ⓡest

Ⓡice

Ⓒompression

ⓔlevation

- ✓ **Factor in Physiotherapy**
- ✓ **Factor in a PHONE CALL**

Australian Haemophilia Centres

		Phone	Phone (AH)	FAX
ACT	Haemophilia Clinic The Canberra Hospital	02 6244 2188	02 6244 2222	02 6244 2271
NSW	Haemophilia Treatment Centre Calvary Mater Newcastle	02 4921 1240	02 4921 1211	02 4960 2136
	Haemophilia Treatment Centre Royal Prince Alfred Hospital	02 9515 7013	02 9515 6111	02 9515 8946
	Centre for Children's Cancer and Blood Disorders Sydney Children's Hospital	02 9382 1690	02 9382 1111	02 9382 1789
	Factor Zone - Haemophilia Treatment Centre The Children's Hospital at Westmead	02 9845 1138	02 9845 0000	02 9845 2041
	Bleeding Disorders Clinic Prince of Wales Hospital	02 9382 9013	02 9382 2222	029382 9116
	Bleeding Disorders Clinic Westmead Hospital	02 9845 6274	02 9845 5555	02 9689 2331
NT	Haemophilia Treatment Centre Royal Darwin Hospital	08 8944 8346	08 8922 8888	08 8922 8843
QLD	Queensland Haemophilia Centre Royal Brisbane and Women's Hospital	07 3646 5727	07 3646 8111	07 3646 4221
	Queensland Haemophilia Centre Child and Adolescent Service Royal Children's Hospital	07 3636 9030	07 3646 8111	07 3636 1552
SA	South Australia Haemophilia Treatment Centre Royal Adelaide Hospital	08 8222 4396	08 8222 4000	08 8222 5940
	South Australia Haemophilia Treatment Centre Women's and Children's Hospital	08 8161 7411	08 8161 7000	08 8161 6567
TAS	Pediatric Oncology-Haematology Clinic Royal Hobart Hospital	03 6222 8045	03 6222 8308	03 6222 6767
VIC	Ronald Sawers Haemophilia Centre The Alfred Hospital	03 9076 2178	03 9076 2000	03 9076 3021
	Henry Ekert Haemophilia Treatment Centre The Royal Children's Hospital	03 9345 5099	03 9345 5522	03 9349 1819
WA	The Haemophilia Centre of WA Fremantle Hospital	08 9431 2210	08 9431 3333	08 9431 2881
	The Haemophilia Centre of WA Princess Margaret Hospital	08 9340 8682	08 9340 8222	08 9341 9842
	The Haemophilia Centre of WA Royal Perth Hospital	08 9224 2897	08 9224 2244	08 9224 8475



If you would like more information about MyABDR, visit the MyABDR website:
W: www.blood.gov.au/myabdr
T: 13 000 BLOOD (13 000 25663)
E: myabdr@blood.gov.au

Or contact Haemophilia Foundation Australia
W: www.haemophilia.org.au/myabdr
T: 1800 807 173
E: hfaust@haemophilia.org.au
 There is also a MyABDR feedback form on the HFA website.

MyABDR is a collaboration between Haemophilia Foundation Australia (HFA), the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of all Australian governments.