



FAIR TIME FOR WOMEN COALITION

Diagnosis, Care,
and Treatment

TOOL

Kit

Welcome

The FAIR Time for Women Coalition is dedicated to creating a grassroots movement to assist women, girls, and those assigned female at birth in receiving care for their bleeding disorders. To assist, we have created the Diagnosis, Care, and Treatment Toolkit.

We hope that this toolkit will be a resource of tips, tricks, and recommendations on how you can advocate for the care options you need. We encourage you to fill out the templates provided and share with your medical providers.

This toolkit was created with input from the FAIR Time for Women's Communications and Advocacy Working Groups and the Advisory Board. Special thanks to Dr. Danielle Nance for providing the content for this toolkit.

Recommendations

Day to Day Work



Keep a travel/diagnosis letter on you at all times in case of an emergency and to share with other providers.



Stay in communication with your medication representative for new treatment options.



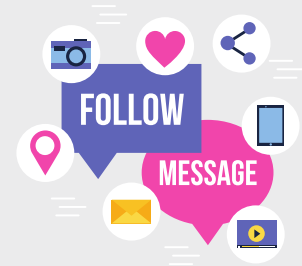
Wear a medic alert necklace/bracelet in case of an emergency.



Connect with your local and national bleeding disorder chapters to stay active in the community.



Have an emergency bag with extra pads, tampons, pain pills, bandages, wipes, etc.



Join bleeding disorder social media groups and connect with others like you.

Recommendations

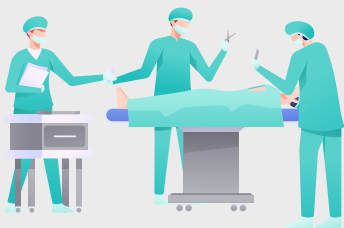
When you have or suspect a bleed, let your medical provider know if you have the following issues:



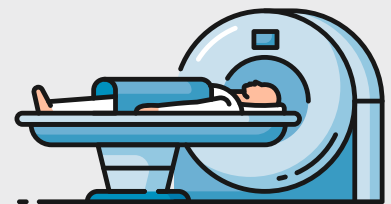
If symptoms of pain do not respond to treatment, or get worse, let your medical provider know.



If your symptoms are not from bleeding, ask for an explanation of what those symptoms are from, and what can be done to help you feel better.



If you have new symptoms, or if you have surgery coming up, tell your medical provider.



If imaging is recommended to document a bleed, then do the imaging.

Tips & Tricks

As you're heading into your next hematology appointment, consider the following tips to make your appointment the most effective.



Write down your top 3 needs/concerns on a list and take it with you to your appointment. Document any issues with photos and details.



Be prepared with questions. Clinic visits generate work beyond the time the patient experiences with the provider. There may only be a short amount of time, typically 20 minutes at most to listen to you. The rest of the time will be coordinating your care needs behind the scenes.



Track your periods, bleeds, or other concerns and bring to your appointment.

Tips & Tricks

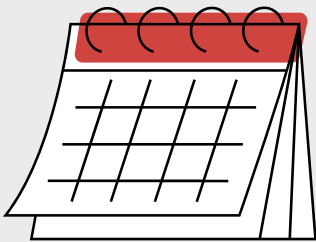
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Bring a “listener” with you to help support you.



Ask for a travel/diagnosis letter for emergencies and to share with other providers.



Schedule another appointment if you need more time to ask questions.



Notes:

Symptom Tracker

It's always a good idea to bring documentation to your medical appointments.



Once a day or once a week: record symptoms of swelling, pain and or things worrisome for bleeds – take this to your provider visit.



Menstrual symptoms: Document how often you have to change your pads or tampons, and how many days you bleed. Capture any details that describe the challenges you have with your period. (Changing sheets in middle of the night, wearing double pads, changing clothes, etc.).



Record the medications you take around the time of the pain: Especially medicines that might have naproxen (Aleve) ibuprofen (Advil) or aspirin (Excedrin, Pepto Bismol, Alka Seltzer) and antidepressants (Zoloft, Prozac etc.).



Record if you miss work or school or if you have to stay home and miss social activities because of pain or bleeding symptoms.

Symptom Tracker



Notes:



Write down your top three needs/concerns to discuss with your doctor.



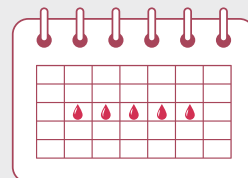
Record your bleeding/bruising incidents:

- Location of bleed/bruise
- Amount of swelling
- Pain level
- Incident that caused bleeding/bruising
- How many days you missed school/work

Symptom Tracker



Notes:



Record your menstrual symptoms:

- How often you change tampons/pads
- How many days you bleed
- How often you have to get up at night to change protection
- How many days you missed school/work/social events



Record your medications taken around the time of pain:

- Pain medications
- Antidepressants
- Factor products (note if they are family member's)
- Other



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Calendar

Record any bleeding episodes and your menstrual symptoms.

SUN	MON	TUES	WEDS	THURS	FRI	SAT

Treatment Log

Track your symptoms and treatments. Another option would be to download a treatment log app for your phone.

DATE	SYMPTOM	TREATMENT	LABEL/NOTE



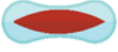
Menstrual Tracking Log




Track your menstrual cycle below or use an app on your smartphone.

BETTER YOU KNOW | Menstrual Chart & Scoring System

INSTRUCTIONS: Write down the number of pads/tampons used per day based on how saturated they are for each day of your period. If longer than 10 days, please continue to score using a second chart. If you have any blood clots, note how many and the size of each clot for each day. See scoring system on the right for how to measure clot size. If you have any flooding or gushing that is enough to affect your daily activities and quality of life, put a check for that day.

DATE OF START _____ / ____ / ____
month day year

Pads	Day 1	2	3	4	5	6	7	8	9	10
										
										
										
Clots: size and # Flooding: check mark										

Tampons	Day 1	2	3	4	5	6	7	8	9	10
										
										
										
Clots: size and # Flooding: check mark										



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Scoring system

Pads

- 1 point for each lightly stained pad
- 5 points for each moderately soiled pad
- 20 points for each completely saturated pad

Tampons

- 1 point for each lightly stained tampon
- 5 points for each moderately soiled tampon
- 10 points for each completely saturated tampon

Clots

- 1 point for small clots (like a grape)
- 5 points for large clots (like a strawberry)

TOTAL POINTS

If your total is more than 100, see a health care professional.

Source: Jenny M. Higham, P. M. S. O'Brien, R.W. Shaw. Assessment of menstrual blood loss using a pictorial chart. *British Journal of Obstetrics and Gynaecology*, August 1990, vol. 97, pp. 734-739



Diagnosis Test Codes

If you suspect you have a bleeding disorder, your medical provider may request the following tests.

TEST NAME	TEST
Complete blood count	85027
Platelet function	85576
Activated partial thromboplastin time (aPTT)	85730
Prothrombin time (PT)	85610
Fibrinogen activity	85384
von Willebrand factor ristocetin cofactor test (VWF.Rco), also known as VWF activity test	85245
von Willebrand factor (VWF) antigen test (VWF-Ag)	85246
VWF collagen binding (VWF:CB)	83520
Factor VIII clotting activity (FVIII:C)	85240
Factor IX activity level (FIX:C)	86298

Join the Movement


Everyone is invited to join our grassroots movement and advocate for health equity for all with bleeding disorders. Like, follow and share with your family and community!


FAIR RESOURCES

 Website: ftfw.org

 LinkedIn: [fairtime4women](https://www.linkedin.com/company/fairtime4women)

 Twitter: [fairtime4women](https://twitter.com/fairtime4women)

 Instagram: [fairforwomen](https://www.instagram.com/fairforwomen)

 Facebook Page: [fairtimeforwomen](https://www.facebook.com/fairtimeforwomen)

 Facebook Group: [/groups/fairtimeforwomen](https://www.facebook.com/groups/fairtimeforwomen)