

AA&MDSIF Treatment Tracker Tools

Current therapies to treat bone marrow failure diseases often require repeated cycles before you notice an effect and improvement in your quality of life. Stopping treatment early may result in less desirable results. For patients undergoing treatment for aplastic anemia, MDS and PNH, treatment can be long and improvement can be slow.

Using the pages of the AA&MDSIF Treatment Tracker can help patients monitor their progress, record their reaction to therapies and even track their medication. The information can be shared with doctors and family, allowing everyone to see the progress with treatment or supportive therapies.

Use the “Symptom Snapshot” to keep track of how you feel during and after your treatments. Each day enter a score from “0” (☹) to “10” (☺) to show how you are feeling for common symptoms and side effects. You can add these up to create a total score, your “snapshot” at the bottom of the page. Tracking your symptoms and any treatment side effects regularly, will help you and your medical team see how you are doing while you are in treatment. Your doctor may be able to provide other therapies to help manage any symptoms and side effects you experience. Bring a copy of this page to your healthcare team or share with your family members.

When you have lab blood work results, you can record your lab work data to keep track of even small changes over time, in one easy location! You can record your lab work results for easy review and sharing with family or your healthcare team.

Use the Treatment Tracker page to document the date and type of treatments or supportive therapies you receive. Compare your treatments with your Symptom Snapshot to keep track of how you are feeling as your treatment progresses.

Getting Started: Each day, use the “Snapshot Score” to track and record the day-to-day symptoms and side effects related to your bone marrow failure disease and treatment. Total your Snapshot score at the bottom to help you see even small changes over time. You can also track your treatments (along with your lab work results) so that you can easily see how your treatments affect your overall quality of life.



How do you
feel today?



Symptom Snapshot — How are you feeling?

Month:	"0"	"10"	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31				
Sample	<i>Not Well</i>	<i>Feel Great</i>	10	9	8	7	6	5	6	7	6	4	3	4	4	5	7	8	9	9	10	9	9	8	8	8	7	6	7	7	8	8	9				
Fatigue and Energy Level	Exhausted	Normal energy level																																			
Appetite (are you eating?)	No appetite	Normal appetite																																			
Nausea or Vomiting	Severe nausea	No nausea or vomiting																																			
Diarrhea	Severe diarrhea	No diarrhea																																			
Infections	Severe infection	No infection																																			
Mouth Sores	Severe sores	No sores																																			
Pain (joint or muscle)	Severe pain	No pain																																			
Edema or Swelling	Severe swelling	Normal limbs																																			
Constipation	Severe	Regular bowel movements																																			
Other	Severe problem	Not a problem																																			
Other	Severe problem	Not a problem																																			
Total to see your daily symptom score																																					



Treatment Tracker

	Type of treatment	Date	Notes	Date	Notes
Medication	Azacitidine (Vidaza®)				
	Decitabine (Dacogen®)				
	Lenalidomide (Revlimid®)				
	Eculizumab (Soliris®)				
Growth Factors	Red cell growth factors				
	White cell growth factors				
	Platelet growth factors				
Transfusion	Red blood cells				
	Platelets				
Iron Overload Treatment	Chelation: Deferoxamine (Desferal®)				
	Chelation: Deferasirox (Exjade®)				
	Phlebotomy for iron overload				
Antibiotics					
Immunosuppressive Therapy	Anti-thymocyte globulin (ATG)				
	Cyclosporine (Neoral®, Sandimmune®)				
	Steroids (Prednisone®, Dexamethasone®)				
Chemotherapy					
Stem Cell Transplant					
Other Treatments					
Clinical Trials					



Lab Work

Lab Test	Date	Date	Date	Date	Date
Complete Blood Count					
White blood cell (WBC)					
Red blood cell (RBC)					
Hemoglobin (Hgb)					
Hematocrit (Hct)					
Mean Corpuscular Volume (MCV)					
Platelet Count					
<i>% Polys/Segs/Neutrophils</i>					
ANC					
Bone Marrow Studies					
Percent Blasts					
Ring Sideroblasts					
Karyotype					
Metabolic Panel					
Creatinine					
Albumin					
ALT					
AST					
Bilirubin					
Other Lab Results					
Ferritin level					
Erythropoietin (EPO)					
Folate					
TSH (Thyroid Stimulating Hormone)					
Vitamin B12					