

Pediatric Hemophilia Activities List

Parents' version

An activities questionnaire for children aged 4-17 with hemophilia.

Date completed	:
Date of birth	:

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Introduction

This is the Pediatric Hemophilia Activities List, or 'PedHAL' for short. This list describes a number of activities that can cause problems for children and teenagers with hemophilia. We would like to use this list to find out whether they are problems for your child, too.

General comments

Answer the questions based on **your child's** experiences. The aim is to give the answer that you think best describes your child's situation. For each of the activities, you are asked to indicate whether your child has had problems with the activity in the past month due to hemophilia. There are seven possible answers from which to choose. Please mark your answer by placing a cross in the correct box.

Example:

In the previous month, did your child have any difficulty, due to hemophilia, with:

	N⁄A	Impossible	Always a problem	Usually a problem	Sometimes a problem	Almost never a problem	Never a problem
Bicycling	\square_8	\square_1			\Box_4		\square_6

Please choose only one box per question. Use the 'N/A' option if your child never carried out the activity (or never needed to). The difference between 'Impossible' and 'Always a problem' is that 'Impossible' means your child was unable to carry out the activity, whereas answering 'Always a problem' means that your child always had problems with the activity, but he/she was still able to carry it out.

It is very important that you answer all of the questions. If you have doubts about answering a question, try to give the anwer that comes closest to what you think is right for your child.

This questionnaire takes about 10 minutes to complete.

Sitting/kneeling/standing

	N⁄A	Impossible	Alwaysa problem	Usually a problem	Sometimes a problem	Rarely a problem	Never a problem
Sitting down (e.g. on a chair or couch)	□ ₈	\square_1	\square_2	\square_3	\square_4		\square_6
Sitting on the ground (e.g. when watching TV or playing)	□ ₈	\square_1	\square_2				\square_6
Standing up from a chair with arm rests	\square_8	\square_1		□₃		\square_5	\square_6
Standing up from a chair <i>without</i> arm rests	\square_8			□3	\square_4	\square_5	\square_6
Kneeling/squatting (bending his/her knees)	□8			\square_3	\square_4	\square_5	\square_6
Squatting for long periods (knees not touching the ground)	□8			\square_3	\square_4		\square_6
Bending over forwards		\square_1	\square_2	\square_3	\square_4		\square_6
Standing still for a short period (less than 10 minutes; e.g. waiting in line at a shop)					\square_4		
Standing still for longer periods (from 10 minutes to 1 hour)		\square_1	\square_2	\square_3	\square_4		\square_6
Standing still for very long periods (more than 1 hour)	□ ₈			\square_3	\square_4		\square_6

Legs

nemophilia, with.	N⁄A	Impossible	Alwaysa problem	Usually a problem	Sometimes a problem	Rarely a problem	Never a problem
Walking short distances (less than 10 minutes)	\square_8	\square_1		\square_3	\square_4	\square_5	\square_6
Walking longer distances (from 10 minutes to 1 hour)	\square_8	\square_1		\square_3			\square_6
Walking long distances (more than 1 hour)	\square_8	\square_1		□ ₃	□4		\square_6
Walking on an uneven surface (e.g. a bumpy road, high curbs, doorsteps)	\square_8		D 2		\square_4		\square_6
Walking on a soft surface (e.g. on the beach)				\square_3	\square_4		\square_6
Strolling (e.g. a day at the zoo)			\square_2	\square_3	\square_4	\square_5	\square_6
Running (e.g. to catch the bus, or catch up to a friend)		\square_1	\square_2	\square_3	\square_4		\square_6
Jumping (onto/off something)	\square_8	\square_1	\square_2	\square_3	\square_4		\square_6
Walking <i>up</i> a flight of stairs (a flight of stairs is around 14 steps)	\square_8	\square_1	\square_2	\square_3	\square_4		\square_6
Walking <i>down</i> a flight of stairs	\square_8	\square_1	\square_2	\square_3	\square_4		\square_6
Walking or riding up a small hill or slope without help	\square_8	\square_1	\square_2	\square_3	\square_4		\square_6

Arms

In the previous month, did your child have any difficulty, due to hemophilia, with:

	N/A	Impossible	Alwaysa problem	Usually a problem	Sometimes a problem	Rarely a problem	Never a problem
Carrying large or heavy objects with two hands (e.g. a big box of toys, a stack of books)	\square_8	\square_1	\square_2	\square_3	\Box_4	□₅	\square_6
Stretching to reach something above head- height (e.g. a high shelf)	\square_8	\square_1	\square_2	\square_3		□₅	\square_6
Fine hand movements (e.g. picking up a Lego, playing computer games)	\square_8	\square_1	\square_2		\square_4		\square_6
Writing (e.g. schoolwork or homework)	\square_8				\square_4	\square_5	\square_6
Leaning on his/her arms	\square_8	\square_1		\square_3	\square_4	\square_5	\square_6
Shaking hands with someone				\square_3	\square_4	\square_5	\square_6

Use of transport

	N⁄A	Impossible	Alw ays a problem	Usually a problem	Sometimes a problem	Rarely a problem	Never a problem
Bicycling	\square_8	\square_1	\square_2	\square_3	\square_4	\square_5	\square_6
Getting in and out of the car	\square_8	\square_1	\square_2	\square_3	\square_4		\square_6
Using public transportation (bus, train, subway, streetcar)	\square_8	\square_1		\square_3	\square_4		\square_6

Self care

	N/A	Impossible	Always a problem	Usually a problem	Sometimes a problem	Rarely a problem	Never a problem
Drying his/her entire body	\square_8	\square_1		\square_3	\square_4		\square_6
Putting on a t-shirt, jumper, etc.	\square_8	\square_1	\square_2	\square_3	\square_4		\square_6
Putting on trousers	\square_8	\square_1	\square_2	\square_3	\square_4		\square_6
Putting on shoes and socks	\square_8	\square_1		\square_3	\Box_4		\square_6
Wiping himself/herself after using the toilet	\square_8	\square_1					\square_6
Fastening a hood or the top button of his/her jacket	\square_8				\square_4		\square_6
Buttering bread or making a sandwich				\square_3	\square_4	\square_5	\square_6
Opening a bottle of water, juice, etc.			\square_2	\square_3	\square_4	\square_5	\square_6
Brushing his/her teeth		\square_1	\square_2	\square_3	\square_4	\square_5	\square_6

Household tasks

	Ν⁄Α	Impossible	Alw ays a problem	Usually a problem	Sometimes a problem	Rarely a problem	Never a problem
Chores in the house (e.g. making his/her bed, cleaning his/her room, setting the table)	\square_8	\Box_1	\square_2	\square_3	\square_4	□₅	\square_6
Outside chores (e.g. taking out the garbage, washing the car)		\Box_1		\square_3			\square_6
Other household chores (e.g. running errands, walking the dog)							
	5)					



Leisure activities and sports

	N/A	Impossible	Alw ays a problem	Usually a problem	Sometimes a problem	Rarely a problem	Never a problem
Going out and dancing (e.g. the movies, pub, disco, entertainment centre, museum, etc.)		\square_1					
Playing outside, alone or with others		\square_1				□₅	\square_6
School sports: exercises and gymnastic equipment		\square_1			\square_4		\square_6
School sports: athletics (e.g. long jump)	\square_8	\square_1			\square_4		\square_6
School sports: ball sports (volleyball, softball)	\square_8				\square_4		\square_6
Playing non-contact team sports (e.g. volleyball, basketball)	□8			\square_3	\square_4	\square_5	\square_6
Playing contact team sports (e.g. hockey, soccer)		\square_1	\square_2	\square_3	\square_4		\square_6
Individual non-contact sports (e.g. tennis, cycling)		\square_1		\square_3	\square_4		\square_6
Individual contact sports (judo, karate, boxing, kickboxing)	\square_8	\square_1	\square_2	\square_3	\square_4	\square_5	\square_6
Taking part in a sports event over the course of several days (e.g. swim- ming, walking, cycling or a sports tournament)		\Box_1		\square_3	\square_4		\square_6
Going to school camp or summer camp	\square_8			\square_3	\square_4	\square_5	\square_6

Adaptations and using an aid

Your child may have been using various types of modified equipment or aids to enable him/her to carry out his/her activities. We want to know about the aids that your child used on a typical day (so do not include the use of crutches after a joint bleed).

The questions below ask about these modified equipment and aids.

Do your child have a bike that has been modified?

- □ No, my child does not have a bike
- □ No, my child's bike has not been modified

Yes, my child has a bike with (several answers allowed):

- □ Three wheels
- □ Power Assist system
- □ A moped or motorised bicycle
- □ Other (please specify):
- □ Other (please specify):
- □ Other (please specify):

Do your child use any aids when carrying out his/her daily activities?

- □ No, my child doesn't use any aids
- Yes, my child uses (several answers allowed):
 - □ A crutch (1 crutch/cane)
 - □ A pair of crutches
 - □ Wheelchair
 - □ Walker
 - Other (please specify):
 Other (please specify):

If there are any other activities that you would like to add to the list, please describe them below:

Thank you for your cooperation.