

Medical Day Unit (MDU)

Henoch-Schönlein Purpura (HSP)

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested

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Family Held Record

NOTES:

Henoch-Schönlein Purpura (HSP)

FAMILY FACTSHEET

What is HSP?

Henoch and **Schönlein** are the names of the doctors who described this condition. **Purpura** is the medical name for the rash that is usually seen. Recently, it has been renamed Immunoglobulin A vasculitis (IgA vasculitis). Both names are used.

HSP is an illness, which causes skin rash, painful / swollen joints, tummy pains and may also affect your kidneys. It is caused by inflammation of blood vessels, which in medical language is called **vasculitis**.

HSP occurs most commonly in children, but all ages can be affected. It is often a mild illness. The first episode of HSP can last from a couple of weeks to several months with symptoms flaring and reducing during this period. About half of the people who get HSP go on to have further episodes. Most recover without problems, irrespective of how long they have had symptoms.

In about half of children with HSP, small amounts of blood or protein are found in the urine. Very rarely there may be longer term kidney problems and because of this we advise regular urine checks for at least 6 months after the HSP has gone away.

There are usually no special blood tests or scans needed in HSP, as the problems you report and the rash, are generally enough for accurate diagnosis.

What causes HSP?

HSP seems to be an unusual reaction to the body's immune system in response to infection. It may occur following an infection of the throat or airways. It is not known why some people are affected whilst others are not. HSP is not inherited and it is not contagious.

How is HSP treated?

Usually HSP gets better without any treatment. However you may need some medicines to help with joint or tummy pain.



Joint problems – Rest to start, mobilise early

HSP can cause pain and swelling in joints (most often knees and ankles). Anti-inflammatory medicines, such as ibuprofen, can help with these pains. Painful or swollen joints can be rested, but it is important to get them moving as soon as possible once the pain has settled. HSP does not cause any long term joint problems

Tummy pains – If severe or blood in bowel motions: See your doctor

Sometimes tummy pains can be quite troublesome. There may also be some blood in the bowel motions. If the tummy pains are severe or you see blood in the stools, you should return to your GP or the A&E Department. Occasionally steroid medication may be needed to reduce severe tummy symptoms.



Contact for advice

You can contact the Medical Day Unit (MDU) on 0151 252 5767, Mon-Fri 9-5pm, if you are concerned, or need further advice about joint or tummy problems.

Checking the Urine

Everyone with HSP will be asked to return to MDU for a urine test (& blood pressure check) around 1 week after diagnosis. If these checks are normal the test will be repeated at 1 month, 3 months and 6 months after the episode of HSP.

If the urine stays normal, you will be discharged after the 6 month check, without the need for further follow-up.

If the nurses find blood or protein in the urine it does not mean that there are long term problems with the kidneys, but it does mean more tests may be needed.

Your HSP monitoring booklet will include details of your review appointments, and information on what action may be required if something is found.

Very few children develop further problems, but it is important that you return for these checks, in case problems arise which need treatment. If you have any problems or concerns in between review appointments, you can contact the nurses on MDU, see your GP or return to A&E.

NOTES:

IF PROTEINURIA

Review at 2 weeks, 4 weeks, 2 months, 3 months, 4 months & 6 months.
Discharge if urinalysis is clear at 6 months.

FAMILY NOTE: If protein is found in the urine (proteinuria), you will need to have more frequent monitoring and some additional tests each time you come.

These tests tell us more about the way the body is reacting to the HSP. It does not mean that the kidneys have been damaged, but will allow us to identify any further problems immediately and treat as appropriate.

Date attended	Checks done	Comment
___ / ___ / ____ (due at 2 weeks)		
___ / ___ / ____ (due at 4 weeks)		
___ / ___ / ____ (due at 2 months)		
___ / ___ / ____ (due at 3 months)		
___ / ___ / ____ (due at 4 months)		
___ / ___ / ____ (due at 6 months)		

NOTES:

ABOUT THIS RECORD

The family held record is designed to record the monitoring of Blood Pressure and Urine following Henoch Schönlein Purpura (HSP).

This is routine for all children because of the small risk of kidney problems following the disease.

Most children will only need to attend for routine blood pressure and urine tests. Normally, children will be discharged after 6 months with no further follow-up required.

Only page 4 of this family held record will need to be completed and you will be asked to return the booklet on discharge.

If any signs of Hypertension (high blood pressure), Haematuria (blood in the urine) or Proteinuria (protein in the urine) are detected, additional tests will need to be performed.

The remaining pages of this record are for monitoring of Hypertension, Haematuria and Proteinuria, if these are found.

Please don't let the information in the rest of the booklet worry you. Problems are rare, and usually easy to treat, as long as they are detected early.

Please bring this record with you to the clinic every time you attend.

If you have any other concerns, in-between appointments, please contact your GP in the usual way.

We would like to be able to detect any problems which may occur at the earliest opportunity, but we can only do this with your help. Please make sure you attend for checks as recommended by your doctor.

If you are unable to attend for your appointment, please ring MDU to rearrange it (Tel: 0151 252 5767). If you miss an appointment you will not be sent another automatically. You will need to ring up and make another appointment yourself.

Please help us to help you, by attending regularly.



URINE AND BLOOD PRESSURE CHECKS

This page records when tests are due and the results of routine screening.

Date presented	Urinalysis & BP	Comment
___ / ___ / ____	Results on presentation in A&E	

FAMILY NOTE: If these results are satisfactory, you will need to be checked at 1 week, 1 month, 3 months and 6 months. If everything remains normal you will then be discharged with no need for further follow-up.

ROUTINE FOLLOW-UP: URINE & BLOOD PRESSURE CHECKS on MDU

Dates	Routine monitoring (Urinalysis & BP)	Comment
___ / ___ / ____	1 week after presentation	
___ / ___ / ____	1 month after presentation	
___ / ___ / ____	3 months after presentation	
___ / ___ / ____	6 months after presentation	

FAMILY NOTE: If all of the above results are satisfactory, you will not need to return for further checks. Please return this booklet on discharge.

NOTES:

IF POSITIVE FOR BLOOD and / or PROTEIN on presentation

If blood or protein was found in the urine at presentation, further tests will have been performed in the A&E department to find out more. These results will be checked on MDU. Don't worry, this doesn't mean that the kidneys are damaged.

Date performed (in A&E)	Further tests performed in A&E	Comment
___ / ___ / ____		

You will be asked to return for further checks (see page 6). If problems remain, you may need further treatment.

IF HYPERTENSION (confirmed on 3 separate occasions)

If high blood pressure (hypertension) is found, your child will be monitored and treated appropriately. You may need to see a specialist doctor (Nephrologist).

Date	Blood pressure check	Comment
___ / ___ / ____		
___ / ___ / ____		
___ / ___ / ____		

IF HAEMATURIA (without proteinuria) on routine review

If traces of blood are found in the urine (haematuria), without any protein, this is unlikely to need treatment, but some extra tests will need to be done on the day.

Date	Further tests	Comment
___ / ___ / ____		

If blood becomes visible in the urine, and remains for more than 7 days, you may need to see the Nephrologist. This doesn't happen very often with HSP.

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