

Gestational Trophoblastic Disease

Atypical placental site nodule (APSN)

Information for patients, relatives and carers

Introduction

This information leaflet is designed to give you information about atypical placental site nodules (APSN). We hope it will answer some of the questions that you or those who care for you may have at this time. This leaflet is not meant to replace the discussion between you and your medical team but aims to help you understand more about what is discussed.

Atypical placental site nodule (APSN)

Very rarely, tiny amounts of tissue from the placenta stay in the womb after pregnancy. This can grow abnormally. This is called an atypical placental site nodule (APSN).

Over time, the nodules may cause unexpected vaginal bleeding. This leads to investigations such as a biopsy of the womb, which can lead to an ASPN diagnosis. For about 18 in 100 women (18%), the ASPN will have caused cancer or will cause cancer to develop over time.

Your expert medical team will discuss with you what this means and your treatment choices.

Why have I been referred to Charing Cross Hospital?

APSN is a rare condition and Charing Cross hospital is a specialist centre for its treatment.

Diagnosis and treatment

You will have further investigations at Charing Cross hospital including a blood test, MRI, CT and ultrasound tests. Your consultant will discuss the treatment options with you.

The main treatment option is usually a hysterectomy, especially if you have completed your family.

You could choose to have regular observation with blood and urine tests if you have not completed your family or you do not wish to have this surgery.

If you have had multiple pregnancies, we may need to determine from which pregnancy the APSN developed. This genetic test would require a saliva sample from your child or children.

How your clinical nurse specialist (CNS) team help you during treatment

The CNS team are experienced, specially trained nurses who work with the other members of the team to provide medical and psychological care to people with this condition and their families.

Your CNS team will be able to help co-ordinate your care during your treatment.

They can clarify any information, discuss matters important to you, provide emotional support and refer or signpost you to other professionals if required.

It is very important that you are able to have your questions answered and concerns discussed. Your CNS team will make every effort to ensure this happens.

You can contact your CNS team via the Macmillan navigator service on 0203 313 0303.

What is the surveillance programme?

We will monitor you with regular blood and urine samples with the possibility of repeat scans (see follow up schedule below).

Follow-up schedule

Initial assessment: MRI abdomen/pelvis and MRI head, CT chest and Ultrasound Scan pelvis.

Year 1: HCG (the hormone human chorionic gonadatrophin) urine and blood 3 monthly, 6 monthly MRI abdomen/pelvis and chest X-ray.

Year 2: HCG urine and blood 6 monthly, 6 monthly MRI abdomen/pelvis and chest X-ray

Year 3: HCG urine and blood 6 monthly, 6 monthly MRI abdomen/pelvis and chest X-ray

Years 4 + 5: HCG urine and blood 6 monthly, yearly MRI abdomen/pelvis and chest X-ray.

Year 6+ HCG urine and blood yearly

You will be sent reminders of when to do these tests and instructions about how to do them

When can I try to get pregnant again?

If you wish to try for a baby, please speak to a member of the clinical team who will advise you according to your specific situation. This can be at an appointment or by contacting the team if you do not have an appointment coming up.

When will I be discharged?

If no evidence of cancer is found in womb at hysterectomy, you would not require any further follow up. You would be seen in clinic to discuss this before being discharged.

If you choose not to have a hysterectomy, you will follow the surveillance programme (see table)

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: 020 3312 1337 / 1349

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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