

## PATIENT INFORMATION LEAFLET ON HYDATIDIFORM MOLE

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### What is a hydatidiform mole?

In the UK about 1 in 1300 pregnant women have what is called a hydatidiform mole, or molar pregnancy, instead of a normal pregnancy. This can occur

- a) at the time of miscarriage
- b) after your first pregnancy scan

When this happens no baby grows, but instead the placenta (afterbirth) grows as a cluster of cysts which look like grapes. Very rarely this can also happen after the birth of a normal healthy baby.

There are 2 main types of molar pregnancy:

- a) complete hydatidiform mole – no normal pregnancy forms
- b) partial hydatidiform mole – part of the baby forms alongside the molar tissue, but unfortunately cannot survive.

Either way, from the time of conception only the afterbirth grows. This will eventually result in a miscarriage.

### What causes it?

No-one knows why this happens. We do know that it is not due to any infection or intake of any medicines or drugs. It is due to a defect in the way the sperm and egg join together at the beginning of pregnancy.

### Diagnosis and Treatment

A molar pregnancy can be diagnosed when a miscarriage happens. Your EPAU nurse/doctor may notice some of the cysts during a vaginal examination. Sometimes a molar pregnancy will first be suspected when a pregnancy scan is done. If a hydatidiform mole is noticed on scan and there is **no live pregnancy**, then an operation is needed to empty the womb. This is done under general anaesthetic and is called “Surgical Management of Miscarriage”. Occasionally a molar pregnancy is only found after the operation is performed. Following the operation, there is usually no need for any further treatment. However there is a need for follow up tests. We will ask for your written permission to undertake further examination of the pregnancy remains. The permission also includes what options you wish to arrange for the disposal of the pregnancy remains.

### Registration

It is important that you know that you have had a “hydatidiform mole” and that you have follow up checks. When a molar pregnancy is suspected, the pregnancy remains are sent to the laboratory. A few weeks later a report is sent to your gynaecologist and an outpatient appointment will be arranged for you to discuss the results. Since 1973 all molar pregnancies have to be registered at special regional laboratories. After registration your follow up will be arranged by a specialist centre called the Sheffield Trophoblastic Disease Centre at Weston Park Hospital, Sheffield S10 2SJ, telephone 0114 2265205.

The centre in Sheffield will contact you and inform you of further tests or samples that may be needed and when they need to be done. If you have not heard from Sheffield within 3-4 weeks you should enquire with your consultant’s secretary to ensure that you have been registered.

## Follow up tests

The centre at Sheffield will request either a urine or a blood test to check for pregnancy hormone levels called human chorionic gonadotrophin or hCG. The samples are requested every 2 weeks until the hCG level returns to normal. The follow up after this depends on how quickly the hCG returns to normal. Extra blood samples may occasionally be asked for. All the results of your tests will be sent to your GP and to your gynaecologist.

1. If your hCG levels become normal within 8 weeks of your miscarriage:  
You will need to give samples for 6 months. This is likely if you have had what is called a partial hydatidiform mole, or where the original diagnosis was doubtful and you might not really have had a molar pregnancy at all. If you are in this group and wish to try and get pregnant again, you can start trying at the end of the 6 months follow up.
2. If at the end of the first 8 weeks your hCG level is still too high:  
You will need to give samples for 6 months from the date of your first normal result. If you wish to try to get pregnant again, you will be advised to avoid pregnancy for the duration of your sample monitoring.

## What if the tests show further problems?

Most molar pregnancies do not cause further problems. Up to 1 in 10 women will have a persistent or “invasive” hydatidiform mole which will need further treatment with medicines to remove the remaining molar pregnancy. If this happens the centre in Sheffield will advise you. This will be arranged and supervised by Sheffield. If this is needed it is very successful and should not affect future chances of conceiving.

About 2 to 3 in 100 of these pregnancies may develop into cancer. Treatment will again be arranged and supervised by Sheffield.

## Contraception

Hormonal contraception in the form of pills may be taken safely after removal of the mole and before the hCG results return to normal.

## Future pregnancies

Once you have had a molar pregnancy then there will be a 1 in 80 chance of developing another. You will be recommended to have a urine test for hCG 6 weeks **after any future pregnancy** has ended. This is because of a small increase in risk compared with other women. Please inform the centre at Sheffield at the end of any pregnancy.

We also offer an early reassurance scan at 7 weeks in your next pregnancy. Please contact the EPAU to arrange.

## Further advice

Do not hesitate to ask medical staff for further understanding and information. They can be contacted via EPAU on 01423 555373 or Nidderdale Ward on 01423 553647/553648. Further advice can be obtained from the centre in Sheffield. There is a website which you may find useful: [www.molarpregnancy.co.uk](http://www.molarpregnancy.co.uk) . The hospital staff at Harrogate wish you well for your recovery.

If you require this information in an alternative language or format (such as Braille, audiotape or large print), please to a member of the Early Pregnancy Assessment Unit team.

