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WHAT THIS booklet IS ABOUT

Miscarriage is sadly common. Around one in five pregnancies ends this way and it can be a very unhappy experience.

Most miscarriages happen in the first 12 or 13 weeks of pregnancy. It is much less common to miscarry after 13 weeks, and if this has happened to you, you may have been very shocked.

We hope that this booklet helps a little at what might be a very difficult time.

UNDERSTANDING THE medical language

WHAT DO YOU MEAN BY "LATE MISCARRIAGE"?

Late miscarriage is where the baby dies between 14 and 20 weeks of pregnancy.

The booklet doesn't discuss what happens when your baby dies before 14 weeks, even if the actual miscarriage happens later. It also doesn't cover losses which happen at 20 weeks or later - these are called stillbirths.

For some people, hearing the late loss of their baby called a miscarriage can make them even more upset.

"She was a perfect, tiny little baby but officially she never existed. She didn't even have a birth or death certificate. How can someone decide she was never a person?"

THE PHYSICAL process

Your miscarriage may have happened naturally, or you may have had to have your labor induced (started using medication or a medical procedure).

NATURAL MISCARRIAGE

If you miscarried naturally, you may have had period or labor pains – strong contractions in your abdomen or pain in your back. You might have been aware of your bag of water breaking, or it might have stayed intact until your baby was delivered.

It might all have happened quite quickly – and once it started, there wouldn't be any way of stopping it. You might have delivered your baby at home or in the hospital – or perhaps somewhere else.

SILENT MISCARRIAGE

You may have had no sign that anything was wrong with your pregnancy, but an ultrasound showed your baby had died.

You probably had your labor induced to deliver your baby.

Hospital staff might have offered choices about how to manage the labor and they should have told you what was likely to happen.

You might have wanted to start the process of labor as soon as possible, or you may have preferred to go home and think about it for a few days.

Either way, these may have been very difficult and upsetting decisions to have to make.

"My baby was born following several hours of very painful contractions. The release of pain when my waters broke came as a relief, but also a nightmare at the same time."

"When they told me they couldn't find a heartbeat, I think my heart stopped too. I was full of the joys of being pregnant, only to feel I had been hit by a train pital head on."

SEEING AND HOLDING YOUR baby

With a late miscarriage, you are likely able to see your baby and perhaps to hold him*.

You might be very worried about what your baby will look like and choose not to look.

Hospital staff may offer to take a photo of him and save it for you in case you want to look later.

It may be that someone else will describe your baby to you and that will help you decide.

There is no right or wrong thing to do - it depends how you and your partner feel.

"I initially declined to hold my baby. I was so scared about how he might look. But a few hours later I changed my mind and a very kind nurse brought him back into the room. I was pleased I'd seen my baby, who was tiny but perfectly formed."

*Your healthcare provider might not be able to tell you what sex the baby is at birth as it can be difficult to be certain with a tiny baby. To make this booklet easier to read, we have chosen to use the words he, him and his.

WHAT CAUSES LATE miscarriage?

Over the next two pages, we'll list the main causes of late miscarriage. Some can cause earlier losses too. Most miscarriages, at whatever stage, happen because of an abnormality in the baby.

CHROMOSOME PROBLEMS

Examples of chromosome problems are Down Syndrome, Edwards Syndrome and Turner Syndrome.

These are usually one-off abnormalities, happening "out of the blue". But they might be due to a problem that you and/or your partner have, probably without knowing.

With a late miscarriage, it is possible to examine the baby's chromosomes from samples taken from the placenta and umbilical cord, as long as you agree. Your and your partner's chromosomes can be examined from a blood test.

This information will help the genetic counselor to tell you the risk of a similar problem happening again. If your doctor thinks that you have a higher risk than most people of having a baby with a chromosome abnormality, you may be offered extra tests in your next pregnancy.

GENETIC PROBLEMS

Our chromosomes carry our genes. We all have many thousands of genes; we also all have some abnormal genes. Sometimes these genes can cause the baby to die in pregnancy.

Genetic problems are more likely to cause early miscarriage. But if your doctor suspects that a genetic problem caused your miscarriage, s/he might refer you to a specialist to have tests and receive advice about future pregnancies.

STRUCTURAL PROBLEMS

This means problems in the baby's body; for example, Spina Bifida or a congenital heart defect. These are sometimes seen on an ultrasound scan, but sometimes they are only discovered after the baby is born.

If your baby is found to have this kind of problem, you should be offered genetic counselling so that you can find out more about the chances of it happening again.

OTHER CAUSES OF LATE miscarriage

ANATOMICAL PROBLEMS

If you have an unusually shaped uterus, this might have caused your miscarriage. Your doctor might suggest an operation to correct the shape of your uterus.

If you have a weak cervix (sometimes called an "incompetent cervix"), this might have caused your miscarriage.

The cervix (the neck of the uterus) should stay tightly closed during pregnancy. But if it is weak for some reason, it may open as the baby grows bigger, and it won't be able to hold the baby inside.

If your doctor thinks this caused your miscarriage, s/he may suggest that you have a strengthening stitch, called a cervical cerclage, in your next pregnancy. This is usually done under a general anaesthetic at 13 or 14 weeks of pregnancy.

If your doctor is not sure whether this is the cause, then s/he may decide to monitor you closely in your next pregnancy, with regular ultrasounds to check your cervix.

INFECTION

Some infections can cause a late miscarriage, either by infecting the baby or by infecting the amniotic fluid (the liquid around the baby).

<u>Infections directly affecting the baby</u> include parvovirus, cytomegalovirus (CMV), and toxoplasmosis. These infections can cause the baby to die in the womb. They are uncommon and do not usually happen in another pregnancy.

<u>Infections of the amniotic fluid</u> can happen when bacteria (germs) that normally live in the vagina get into the uterus. One example is bacterial vaginosis (BV), a common infection which has been associated with premature (early) labor.

ANTIPHOSPHOLIPID SYNDROME (APS)

APS is a condition that increases blood-clotting. It is sometimes called Hughes Syndrome.

If blood clots too easily during pregnancy, it can cause early or late miscarriage, as well as other pregnancy problems. If you haven't been tested for APS, you might want to ask your doctor to arrange this test. You will have two blood tests, taken at least twelve weeks apart, and if both are positive, you will be diagnosed as having APS.

If you have APS, you will be treated with low-dose aspirin and possibly another bloodthinning drug called heparin in your next pregnancy.

CAN I FIND OUT WHY MY baby DIED?

After a late miscarriage most hospitals offer some tests. They may involve tests of the baby and possibly blood tests for you and your partner. Examination of your baby is called an autopsy.

An autopsy can provide valuable information about your baby, your pregnancy, and your own health. It can also provide information which will help your doctor to care for you in a future pregnancy.

An autopsy also confirms your baby's sex, which might be different from what was thought when the baby was born.

An autopsy does not always provide a reason for a miscarriage. For some parents this is sad and frustrating. But if you are thinking about trying again, it can also be helpful to know that your baby was normal and there was no obvious reason for the miscarriage.

HOW CAN I DECIDE?

To help you decide, you should have the chance to talk about it with someone who understands the process. We also describe what happens during the examination. We have written this in a separate section (on page 8) in case you'd rather not read it. You don't have to feel rushed into making a decision. You may need time as well as clear information to help you decide, and a few days' delay won't make a difference in the findings.

If you decide not to have an autopsy, you can still ask for the placenta to be examined and for an external examination of your baby. This can provide information which may be helpful if you're thinking about trying again.

"We finally agreed on an external examination and a test of the chromosomes. The results were normal, which we found reassuring, even though we still had no explanation as to why we lost our baby."

WHAT HAPPENS IN THE autopsy

If you decide your baby will have an autopsy, it will be carried out by a pathologist, a doctor who specializes in the study of disease and causes of death. The pathologist may specialize in diseases in pregnancy, babies and children.

An autopsy involves examining the baby carefully, outside and inside his body. Small samples of tissue are taken from each organ and are looked at under a microscope. This will show the pathologist if the tissues were developing normally or not.

Sometimes special procedures are also needed, such as:

- Photographs, x-rays, bacteriology and virology to look for infections, and
- Karyotype tests to study the baby's chromosomes. This can usually be done on a small piece of skin.

Sometimes it is only possible to examine an organ after what's called fixation. This means putting the organ in a chemical called formalin for a few days, to help firm the tissues. You will be asked whether you want this to be done.

You may also need to think about what you want to happen to the organs and tissues after examination. It is important to talk this over and ask any questions you have. The organs can be returned to your baby's body after examination, but this may delay the funeral, if you are having one.

The autopsy takes up to several hours to perform. Afterwards, the incisions made to examine your baby internally will be repaired where possible and, if you wish, he can be wrapped or dressed to hide any marks. You can see your baby again afterwards if you want to. You can talk this through with the pathologist or other staff.

The tissue removed during the autopsy will be examined in a laboratory. This can take some time and it may be several weeks before you receive results. Your doctor will probably schedule a follow-up appointment to discuss the results. (See also Follow up, page 13)

WHAT HAPPENS TO MY baby AFTERWARDS?

When a baby is miscarried before 20 weeks of pregnancy, you don't have to have a burial or cremation for him or her. But you may decide to arrange this yourself.

The hospital staff should take time to explain your options and should also give you written information.

They should give you time to think about what you want to do. You may feel too shocked to be able to make a decision right away. This is a decision you probably never imagined that you would have to make.

"I was amazed by how helpful and sensitive the funeral directors were in organizing my baby's burial."

You may want to ask staff to keep your baby until you are ready to decide. They should understand if you feel you cannot make a decision right away.

You can make your own arrangements for a funeral and/or burial or cremation if you prefer. You could talk to a funeral director or a minister of your own faith if you have one.

The hospital chaplain may also be a good source of information, advice and support, even if you don't have any religious beliefs.

"I had to make decisions beyond my wildest dreams. Did I want to cremate or bury the babies? I was making funeral arrangements when all I wanted to do was hold them in my arms and take them home forever."

9

marking YOUR LOSS

Whether or not you have a funeral for your baby, you may feel you want to find ways to mark his or her brief life.

It may be important to you to name your baby. If you do not know whether your baby was a boy or a girl, you could choose a name that could be given to either. Some parents gather mementos in an album or a special box: for example, an ultrasound photo, a hospital bracelet, letters or cards, and maybe a toy or clothes that they had ready for their baby. Some hospitals offer to make hand or footprints of babies miscarried late in pregnancy and may put them in a special memorial card.

Other parents mark their loss in other ways, perhaps planting a bush or tree, making a donation to charity, or creating something else in their baby's memory. Your hospital may have a book of remembrance where you can enter your baby's name and the date of your miscarriage. Some hospitals hold regular remembrance services for babies who died during pregnancy or around birth.

CANIHAVEA certificate FOR MY BABY?

The Office of Vital Statistics does not provide death certificates for babies miscarried before 20 weeks of pregnancy, but it may be possible to have a certificate from the hospital. This would note your baby's name, if you have given one, the date of the miscarriage and maybe some other details. If your hospital does not provide certificates, you could ask whether they would sign one which you provide.

"A couple of weeks after I miscarried we bought two plants and planted them in the garden with a pebble pond and a pear tree in memory of our little one."

HOW WILLIFEEL after THE MISCARRIAGE?

YOUR BODY

After your miscarriage, you are likely to have some bleeding and may have pain like a period. This could go on for several weeks. Contact your doctor:

- if the bleeding or pain increases
- if you have a vaginal discharge that looks or smells bad, or
- if you are worried about any other physical symptoms.

Your healthcare provider can also give you documentation if you need it for work.

Your breasts may produce milk and you might find this very upsetting. A supportive bra can help you feel more comfortable. If your breasts are painful, you might want to take a mild pain-killer such as acetaminophen. If you have a lot of pain and discomfort, talk to your healthcare provider or the hospital staff. You can also use breast pads, which you can purchase at a drug store or supermarket to soak up any leaking milk.

You may feel very tired for a long time after your miscarriage. Your body needs time to recover from labor and maybe also from infection or treatment. If you are producing milk, that can be tiring too. Despite being tired, you may find it hard to sleep.

Emotional distress can be exhausting too, and can affect how you feel physically. Your body may get back to normal quickly, or it may take longer, especially with a later loss.

People have very different feelings about how they look. You might be upset if you still look pregnant and feel better when you can wear your regular clothes again. Or you may feel that getting back to your pre-pregnancy shape is somehow forgetting or betraying your baby. You might not want to let go of the look and feel of pregnancy.

Try to give yourself time to recover. Sometimes the demands of home and work make that difficult. You might feel that the sooner you get back to your usual routine, the quicker you'll feel better. That might work, but don't be too surprised if it doesn't. You may just need more time. It may help to talk to someone who understands. See page 15 for some suggestions.

"I felt tired all the time and didn't want to get out of bed. I had a constant pain in my chest and a heavy feeling all over."

YOUR FEELINGS

There is no right way to feel after your miscarriage. And however you feel, you may show those feelings clearly or you might keep them hidden as much as you can.

For example, you might feel very sad and cry, maybe a lot of the time. But perhaps it doesn't feel natural to cry, or you worry about upsetting other people. Or maybe you worry that if you start crying, you won't be able to stop.

Coming home from hospital without your baby can be hard. If you have bought baby clothes and equipment, or decorated a room, it can be upsetting to see them, though you may find it comforting too.

"For those of us who have undergone the trauma and complex feelings following miscarriage, a little of that pain remains in a corner of one's heart forever." Barbara Dickson, singer and

actress

Here are some of the other ways that women and their partners say they feel:

- Angry sometimes at particular people and sometimes just at the unfairness of it all
- Jealous especially of pregnant women or couples with small babies
- Guilty wondering if the miscarriage was somehow your fault
- Lonely especially if people around you don't seem to understand

You may find it hard to talk about what happened or how you feel. Or you might need to talk, to go over what happened again and again. It can sometimes be hard to find people who are willing to listen. Family and friends might say the wrong thing, try to cheer you up, or just avoid talking about what has happened altogether.

You may find you continue to grieve for your baby for much longer than you, or other people, expect. You might feel you'll never recover. For many people, it is not so much a matter of getting over their loss as learning to live with it. This can take time.

"My husband put all the baby things away out of sight, before I came home. He thought they'd upset me. I got the littlest onesie out and just held it and I cried and cried. It was sort of comforting, in a way."

YOUR partner

Your partner is also likely to be grieving the loss of your baby but you may be coping with your feelings in different ways.

Sometimes partners feel they have to be strong and supportive and so they keep their feelings hidden. The downside is that they may not get the support they need. It may be important to be open with each other.

Your miscarriage might have brought you closer, but it might have put a strain on your relationship and that can be very hard to cope with. If the strain of your loss is pulling you and your partner apart, you may need to look for outside support (see page 15).

You might not have a partner and be dealing with this alone. There is more detail in our booklets *Your Feelings After Miscarriage* and *Partners Too*.

WILLIHAVEANY follow-up?

You should have a follow-up appointment with your healthcare provider a few weeks after your miscarriage. This is the opportunity to get the results of any tests, ask any questions you have and find out about treatment that might help now or in another pregnancy.

It can be useful to take a written list of questions with you, because it's easy to forget once you are there. You might want to make notes of the information you are given, as there may be too much to take in and remember at the time.

"After a month had passed it became more and more difficult to say the right thing. We would talk to try and resolve things, but to no avail. I began throwing myself into work, creating extra work just to pass hours."

WHAT ABOUT TRYING again ?

Deciding whether or not to try again can be difficult and you may have very mixed feelings about another pregnancy. You may want to try again as soon as possible, and feel that being pregnant will help you recover from this loss. But you might also be frightened that it could happen again.

It might be something you don't want to think about at all, at least not now. If you do decide to try again, you may want to talk to your healthcare provider about having extra check-ups or ultrasounds next time.

LATE MISCARRIAGE: A summary

- Miscarriage late in pregnancy is uncommon. You might have been very shocked when it happened.
- Going through labor and delivery can be very upsetting; and you may not be sure if you want to see your baby.
- You might be asked to make very difficult decisions about an autopsy and/or about burial or cremation.
- It might take time for you to decide whether or when to try again.
- You may be very upset that a late loss is called a miscarriage rather than a stillbirth.
- It can help if you have people around you who can understand; and there are other places too where you can find help and support.

"All I wanted to do was get pregnant again, but it took several months to happen and that was an emotional struggle, particularly as my due date came and went. Finally I was pregnant and now have a beautiful little boy, but I still think about the baby I lost most days and he lives on in our hearts."

HELPFUL resources

Compassionate Friends offers support after a child has died through 600 local chapters available

in all 50 states and beyond. www.compassionatefriends.org Phone: 877.969.00101000 Jorie Blvd., Suite 1400ak Brook, Illinois 60523

Miscarriage Matters offers a streaming radio station, live chat service, and mentoring for men and women in English and Spanish. www.mymiscarrigematters.org Phone: 833-MM-HELPS (833-664-3577) 420 Spotsylvania Mall Drive #41242 Fredericksburg, VA 22407

Return to Zero H.O.P.E. is an online resource in that offers support, guidance, and resources for parents and family/friends experiencing pregnancy or infant loss. www.rtzhope.org 43 S. Fair Oaks Avenue Pasadena, CA 91105

Share Pregnancy & Infant Loss Support offers support group meetings, resource packets and private online communities. www.nationalshare.org Phone: 800-821-6819 Email: info@nationalshare.org 402 Jackson Street Saint Charles, Missouri 63301-3468

COPE Line provides immediate phone support to individuals grieving the loss of a child. (516) 364-COPE (2673) - Monday – Friday, 9am-9pm, Saturday – Sunday, 10am-3pm

Grassroots Crisis Intervention provides a 24-hour crisis hotline for families needing help with a personal, mental health, or family crisis. Crisis Hotline: 410.531.6677

National Suicide Prevention Lifeline is a national network that provides 24-hour free and confidential emotional support to people in suicide crisis or emotional distress. Crisis hotline: 1-800-273-8255 Online chat: www.suicidepreventionlifeline.org/chat/

HELPFUL resources CONTINUED

USEFUL READING

About what was lost by Jessica Berger- Ross Published by Penguin Group 2007, ISBN: 977 0 452 28799 0

Miscarriage: Women's experiences and needs by Christine Moulder Published by Routledge 2001, ISBN: 0 415 25489 2

Our stories of miscarriage edited by Rachel Faldet and Karen Fitton Published by Fairview Press 1997, ISBN: 1 57749 033 9

When a baby dies: the experience of late miscarriage, stillbirth and neonatal death by Nancy Kohner Published by Routledge 2001, ISBN: 0 415 25276 8

This booklet has been adapted by **Texas Children's Hospital Pavilion for Women** for use in the United States and produced in association with the **Miscarriage Association**

www.miscarriageassociation.org.uk A UK non-profit organization

These are The Miscarriage Association's sentiments:

Our sincere thanks to Miss Judith Moore, Consultant Obstetrician, Nottingham University Hospitals (City Campus), for her help in writing this leaflet; and to everyone who shared their thoughts and experiences with us.



A SPACE FOR notes

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