SCLERODERMA & RAYNAUD'S UK

Scleroderma and Pregnancy

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This section is for women who have scleroderma and are pregnant or considering becoming pregnant. It contains general information only. It is strongly advised that you talk to your doctor about your particular circumstances.

Women have often had pregnancies before their scleroderma developed (Artlett et al 2011). It is important to be aware that pregnancy can be more complicated if you have scleroderma and you may need much more medical involvement than in previous pregnancies.

70-80% of women will have a successful pregnancy

Will I be able to get Pregnant?

The majority of women with scleroderma will have normal fertility. Young women with scleroderma may have a higher risk of infertility than older women who have had previous children (Lambe et al 2004). It is vital to use effective contraception and talk to your doctor before trying to become pregnant.

"I did not have any problems getting pregnant and my 2 children have no health problems."
Mary, systemic sclerosis and Raynaud's.

"I was unable to conceive. I then came off my medication – methotrexate, and subsequently fell pregnant 20 months later."
Jasdeep, diffuse sclerosis.

"I conceived within 3 months of trying, miscarried at 8 weeks, and conceived again successfully the following month. The miscarriage was not because of my scleroderma but due to my age – I was 40 years old at the time, which can increase the risk."
Stephanie, limited scleroderma.

What are the risks with pregnancy and scleroderma?

There are some extra risks with pregnancy particularly if you have the systemic form of scleroderma.
Until recently the traditional advice was for all women with scleroderma was to avoid pregnancy (Lidar and Langevitz 2012).
Recently it has been shown that 70-80% of women will have a successful outcome of pregnancy.

If you have the localised form of scleroderma, or well-controlled stable systemic sclerosis and do not have any heart, lung or kidney complications it is likely that your pregnancy will be relatively straightforward (Mianti et al 2008; Steen 1999; Lidar and Langevitz 2012).

Possible increased risks for women with systemic disease include:

- Miscarriage (small increase)
- Premature birth and/or small baby
- Pre-eclampsia (high blood pressure with protein in the urine) particularly if you have high blood pressure and/or kidney disease before becoming pregnant
- Kidney failure
- Difficulty placing drips/taking blood due to skin thickening or blood vessel involvement
- Difficulty with general anaesthetic if required due to limited mouth opening

Why is pre-conception care important?
The importance of attending pre-conception care cannot be stressed enough. It is vital if you are considering pregnancy that you ask your GP to refer you to a specialist rheumatologist and an obstetrician with experience in managing scleroderma and pregnancy. They will be able to assess your current health and assess the risks for you and your pregnancy. Some drug treatment may need to be stopped or altered prior to conception or in early pregnancy (Greer et al 2007 p.195-7).

Physical tests are likely to be arranged, including:

- Blood pressure measurement
- Kidney function tests
- Autoantibody tests
- Echocardiography (heart scan)
- Lung function tests

If you have serious complications affecting your heart, lungs or kidneys you may be advised NOT to contemplate pregnancy and to continue with effective contraception (Steen 1999; Greer et al 2007 p.195-7).

If you have a recent diagnosis of scleroderma (within 4 years) you may be advised to delay pregnancy, and continue using effective contraception until your condition is stable (Steen 2007). This is because complications in pregnancy are higher with more recent scleroderma onset.

General pre-conception care is very important and your GP will be able to provide this. If you are overweight (BMI more than 30) it is important to lose weight before getting pregnant. If necessary, you will be given advice on how to achieve this. All women are advised to take folic acid daily prior to conception and for the first 3 months of pregnancy as this reduces the risk of spina bifida in the baby (NICE CG62 antenatal care). These might be prescribed, if not they can be bought "over the counter" at a chemist. You should not smoke, avoid recreational drugs and avoid alcohol. You may be advised to take low dose aspirin (75mg) from 12 weeks of pregnancy as this reduces the risk of pre-eclampsia (NICE CG62 antenatal care).

"My scleroderma symptoms are heightened when stressed. It is so important to avoid stress and adopt some calming techniques."
Sonya, limited systemic sclerosis and Raynaud's.

What will happen during my pregnancy?

It is important that you let your health care professionals know as early as possible in pregnancy so a plan of care can be arranged. In some areas of the UK you can contact a midwife directly who will liaise with the hospital doctors and your GP.

You will be classed as a "high risk pregnancy" (Steen 1999) and will have shared care from a multidisciplinary team including a midwife, obstetrician and rheumatologist. If your local hospital is unable to provide the specialist care you need you may be advised to have your care at your nearest teaching hospital to ensure access to the appropriate specialists. Some hospitals have joint "maternal medicine" clinics where all the specialists who are caring for you attend, so cutting down on the number of hospital visits you need. You will still need support and care from your family doctor and community midwife, who will work in partnership with the hospital team.

Your hospital team will make a personal plan of care for your pregnancy. Your medication will be reviewed. Some common medications are safe in pregnancy (e.g. low dose steroids; calcium channel blockers such as nifedipine) and may be continued. Others (including ACE inhibitors and angiotensin-2 receptors) will probably be discontinued, as they are known to increase the risks to the baby during pregnancy (Nelson Piercy in Greer et al 2007 p.195-7). Your doctors will discuss the risks and benefits of each medication you are taking. Herbal remedies and "over the counter" drugs are best avoided unless you have discussed them with your doctor.

At each antenatal clinic appointment you should expect your blood pressure to be measured and a sample of your urine tested. Your midwife or doctor will discuss the standard screening tests offered to all pregnant women, including testing for certain infections and screening for chromosomal problems in the baby such as downs syndrome. You will be offered at least two ultrasound examinations – one for dating the pregnancy at around 12 weeks and another to exclude major abnormalities at around 20 weeks. You may also need further scans to check on the growth of your baby in the second half of pregnancy, especially if you have any complications such as high blood pressure.

"I was checked over once during my pregnancy by the Rheumatology team and told to get in touch if I needed to but that they would see me after the baby was born. I was under a consultant at the hospital where my baby was due to be born. I saw them regularly and had extra scans to monitor the baby's growth. I had steroid injections to mature the baby's lungs as a precaution as was told I was at a high risk of going in to labour early."
Jasdeep, diffuse sclerosis.

"I have localised scleroderma which I have had since I was 2 years old. I am now 27 and have multiple patches and bands across my body. I was on methotrexate for 7 years from the age of 13 and then another 2 years following a flare-up after that. I have a band going from my back all the way round to the front midline of my tummy. The hardest thing I found is the skin doesn't stretch as well and I get a lot of pain around that area from underlying tissue, as it is so tight. I am currently in my second pregnancy with twins this time. My first is now 2.5 years old."
Carrie, localised scleroderma.

Why do I need to see an anaesthetist?

Most women with systemic sclerosis will be offered an appointment with an anaesthetist during their pregnancy. This is because there are some extra anaesthetic risks associated with scleroderma. It can be more difficult to insert a drip or take blood if you have skin involvement. General anaesthesia, where a tube is inserted down the throat, can be more difficult as mothers with scleroderma may have thickening of the tissues in the throat (Nelson-Piercy 2002). If your anaesthetist thinks this applies to you he/she may advise avoiding general anaesthesia if at all possible and using a spinal or epidural technique instead.

Will my scleroderma get worse in pregnancy?

There is conflicting information whether scleroderma worsens in pregnancy. The majority of women will probably not experience any deterioration. Some women may experience skin thickening (Steen 1999). If you have recent onset disease or kidney involvement there is an increased risk of deterioration in pregnancy and you will be monitored carefully for any signs of this. Heartburn is extremely common in pregnancy and women with scleroderma may suffer more from this (Lydall et al in Robson and Waugh 2013 p.172-3). Your doctor or midwife can give you advice on managing this, for example posture, sitting upright after eating, and eating slowly. Drugs such as ranitidine or omeprazole are safe in pregnancy. They may be prescribed to reduce the amount of acid in the stomach.

"I applied lots of oil to my skin to prevent it from stretching and itching." Jasdeep, diffuse sclerosis.

"The telangiectasia in my nail cuticles disappeared until several months after the pregnancy. My rheumatologist concluded that the pregnancy had suspended scleroderma."
Stephanie, limited scleroderma.

On the positive side, if you suffer with Raynaud's phenomenon as part of your disease, your symptoms may lessen, or temporarily disappear (Chakravarty 2010, Nelson-Piercy) because pregnancy increases your inner body temperature and increases the amount of blood, resulting in more warm blood going to fingers, toes and other extremities.

"I did not have any Raynaud's attacks during my pregnancy. My baby was born in December and I do not remember wearing gloves at the end of my pregnancy."
Jasdeep,
diffuse sclerosis.

Will my baby be affected?

Most babies are unaffected by the mother's diagnosis of scleroderma. A few women with scleroderma have specific autoantibodies called Anti-Ro, Anti-La or antiphospholipid antibodies. If you have Anti-Ro or Anti-La antibodies, these can cross over the placenta and into the baby's blood circulation where they can occasionally cause inflammation of the baby's heart. This is called "heart block" and can interfere with the electrical impulses that keep the heart beating regularly (Greer et al 2007 p.195-7). A special test called a fetal echocardiogram might be required during pregnancy to assess the baby's heart.

If you have antiphospholipid antibodies this can sometimes increase the risks of pre-eclampsia, a small baby and pregnancy loss – your doctor will discuss these risks in more detail with you. If you have any of these antibodies you should be offered regular scans to check on your baby's growth and wellbeing.

Will I need to be in hospital during my pregnancy?

Most women will have a relatively straightforward pregnancy and not need to be in hospital. If any complications start to develop, for example pre-eclampsia (high blood pressure with protein in the urine) or concerns about the baby's growth, you may need to be admitted to hospital for monitoring. This can cause a dilemma if there are other children at home, and it is best to discuss this possibility in advance with family and friends to see if family support could be available at short notice.

What type of birth am I likely to have?

This depends on whether there have been any complications during the pregnancy and how severe your scleroderma is. The majority of women are likely to have a straightforward vaginal birth, especially if you have had vaginal births before. If there is concern about the wellbeing of the baby, or you develop pregnancy complications such as pre-eclampsia or if your scleroderma gets worse you may be advised to have the baby early. This might be by inducing labour with drugs or by caesarean section. Your doctors should fully explain your options to you and you should feel involved in any decision making about the birth.

If you are planning a normal birth, your progress in labour should not be affected by your scleroderma. The anaesthetist may advise that you consider an epidural in early labour so that if there are complications and you need a caesarean birth, the epidural can be topped up for the birth avoiding the need for a general anaesthetic. However it is your choice as to what type of pain relief you wish to use in labour.

"I was originally diagnosed with juvenile myositis when I was a teenager and was later diagnosed with systemic sclerosis. I had a very good care plan in place and was monitored often with extra scans, blood tests and rheumatology appointments. It was agreed I would have a C-section due to breech position and they thought it would be the safest option as he was my first child. I think scleroderma did prevent me from having a 'normal birth', but to be honest I was happy with a C-section and asked for another with my second."

Mary, systemic sclerosis.

"I was 'high risk' and so the consultant requested that the baby be monitored throughout my labour. I had to lie on a bed with monitoring belts wrapped round me. I had drips to speed up my contractions, but the baby 'got stuck' and so I was taken to theatre. The consultant was fully aware of my condition and did everything she could to prevent me from having to have a caesarean. After 21 hours of being in labour my daughter was born - healthy and weighing 6lbs."

Jasdeep, diffuse sclerosis.

What will happen after the birth?

Some mothers find that their scleroderma worsens after the baby is born, so you may be advised to restart any pre-pregnancy medication. You may need to stay in hospital for a day or two longer than other mothers if your symptoms flare up or there have been any pregnancy complications while further investigations are carried out. The hospital will arrange follow-up appointments as required, and also for a midwife to visit you at home. If you have had any kidney complications or pre-eclampsia you will need further monitoring of your blood pressure and kidney function. If your hands are affected by scleroderma you may need assistance with handling the baby.

"During the pregnancy my Raynaud's was so much better and the only medication I took was steroid injects just in case of premature labour. After my pregnancy I did get more scleroderma symptoms such as skin tightness, finger ulcers, acid reflux and joint/muscles problems. I started taking medication after my pregnancy, which helped. The doctors think I was in remission while pregnant and after having the baby my immune system started to attack itself again." Mary, systemic sclerosis and Raynaud's.

Will my baby need any extra checks?

The paediatrician will examine your baby after birth and might need to take some blood from either the baby or the placenta. If your baby is premature, or small for its age, admission to a neonatal unit may be necessary.

If you have Anti-Ro or Anti-La antibodies your baby has a 5% chance of developing a condition known as Neonatal Lupus. This presents at 2-3 weeks of age with a rash giving the appearance of "owl eyes" but fortunately usually resolves by about 6 months of age (Robson and Goddard in Robson and Waugh 2013 pp.2002-5). If you have any concerns about your baby you should speak to your midwife, health visitor or family doctor as a referral to a paediatrician may be necessary.

"I breast fed for 10 months and the number of Raynaud's attacks I had during this time was drastically less than 'normal."
Jasdeep, diffuse sclerosis.

Can I breastfeed?

Breast-feeding is usually encouraged and most medication used for scleroderma is safe to take during breastfeeding. Speak to your doctor about this. In the period after birth, known as the puerperium, the body rapidly returns to the non-pregnancy state and a Raynaud's attack is possible. Raynaud's symptoms can occur on the nipple, which are not only painful but also likely to be mistaken for other breastfeeding complications such as thrush or cracked nipples. (Robson and Goddard in Robson and Waugh 2013 pp.2002-5).

Vasospasm events typically occur after feeding has finished, or on any other exposure to the cold. There is potential for damage and discomfort to the nipple if the baby latches on during a vasospasm event, or while the nipple is constricted, because the nipple will not stretch well.

It is important to inform your midwife or health visitor of your condition and seek advice about hot flannels or warming pads to promote blood flow to the nipple area prior to feeding. Some mothers have found use of a breast pump beneficial whilst their Raynaud's symptoms stabilise.

"The rheumatologist advised that there had been some instances of the umbilical cord deteriorating towards the end of the pregnancy and strongly advised that I had the baby no later than 38 weeks. I was induced at 38 weeks - unsuccessfully - and had my son by C-section a couple of days later. My baby was born at a healthy weight of 7lbs. I breastfed for 2 weeks and had to give up only because nobody had noticed he was tongue-tied and couldn't suck properly - nothing to do with the scleroderma."
Stephanie, limited scleroderma.

Finally

Although there are challenges with pregnancy for women with scleroderma, becoming a mother is a joyous and fulfilling event. The majority of women with scleroderma embarking on pregnancy will have a successful outcome. A positive attitude throughout by the mother-to-be, her family and health professionals will ease the journey through the tribulations of scleroderma to motherhood. The information contained in this leaflet is meant as a guide and is not a substitute for a detailed discussion with your health care professionals.

"I was diagnosed with systemic sclerosis and Raynaud's at the age of 21, and gave birth to my daughter aged 35. Before and since my pregnancy I have only taken Omeprazole regularly, and have an Iloprost infusion every six months. My fingers have atrophied with repeated ulceration and I have pulmonary fibrosis resulting in reduced lung capacity.

I didn't have any difficulties in getting pregnant. We stopped contraception in January and then that May I tested positive. I started to feel fantastic. Like a superwoman, and ridiculously sexy. My energy levels went through the roof, and remained high until the final month of my pregnancy. My Raynaud's seemed to disappear and apart from the nausea when smelling garlic I had a healthy appetite to match.

The downside is that I became allergic to my cat and developed severe and frequent aspiration, which was misread as coughing asthma. I went on to a brown inhaler to ease the symptoms. I was also advised to stop taking Omeprazole, but the Gaviscon substitute was inadequate causing me to have constant reflux and coughing during the last months. My blood pressure also lowered further meaning I had to be on guard for dizzy spells. In the last few weeks at night my leg felt like it was completely dead.

I had regular contact with my rheumatologist, cardiologist and obstetrician from 12 weeks, with scans every 4 weeks. The concern was that I would deliver early via C-section, but I was confident that I would be able to reach full-term.

I used Diprobase cream everyday and was able to keep my skin soft throughout my pregnancy.

My daughter was a week overdue, born at the start of 2006. I spent a week in hospital being induced, but she was finally delivered via emergency caesarean as the monitor showed that her heartbeat was decreasing. Due to my Raynaud's there was a difficulty in cannulation and administering the epidural. I remained in hospital for a week post-natal before being discharged.

After about 3 weeks it became clear that my milk had not developed enough to feed my daughter and she was losing weight. Subsequently I moved on to formula and my daughter thrived, and is completely healthy.

My scleroderma symptoms have worsened steadily since giving birth, but I am still the primary carer for my daughter, and with limited medical intervention, so I am still able to manage."

Sonya, limited systemic sclerosis and Raynaud's.

Glossary

Fibrosis
The thickening and scarring of connective tissues (i.e. the skin and internal organs), usually as a result of injury and common in people with systemic sclerosis.

Myositis
Inflammation and degeneration of muscle tissue. See also Myositis UK - www.myositis.org.uk

Pre-eclampsia
A condition that affects some pregnant women, usually during the second half of pregnancy (from around 20 weeks) or soon after their baby is delivered. Early symptoms include high blood pressure, blood in the urine, severe headaches, swelling of the ankles, feet, face and hands, vision problems and pain just below the ribs. If you notice any symptoms you should seek medical advice immediately. More information can be found on the NHS Choices website.

Puerperium period (or post partum or postnatal)
The time from the delivery of the placenta through the first few weeks after the delivery. This period is usually considered to be 6 weeks in duration.

References: For a full list of references, please email info@sruk.co.uk

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