

# SYSTEMIC LUPUS ERYTHEMATOSUS AND WOMEN'S HEALTH

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## What is lupus ?

- Systemic lupus erythematosus (SLE) is an autoimmune disease in which the body's immune system attacks the body's own tissues resulting in inflammation.
- The immune system is the body's mechanism to fight against infections such as bacteria and viruses, by producing cells called antibodies.
- In people with lupus, abnormal antibodies are produced which target the body's own tissues and cause inflammation and tissue damage.

## Who develops SLE?

- SLE is primarily considered a disease affecting women in child bearing age.
- SLE is more common in women than in men
  - Childhood SLE can present before the age of 15 years, and is 3-4 times more common in girls than boys.
  - During the child bearing years, typically 15 to 35 years of age, lupus is 7 to 15 times more common in women than in men.
  - During post menopausal years, women are 8 times more likely to develop the disease than men.
- In the US, African-Americans, Asians and Hispanic Americans are more likely to develop the disease as compared to Americans with European descent.

## How does lupus present ?

- The antibodies formed in lupus can attack any part of the body, hence lupus can affect any organ of the body.
- The spectrum of the disease is very variable. It ranges from mild disease, primarily rashes and joint pain, to severe disease involving the kidneys or the brain.
- Some of the most common manifestations of lupus include skin disease causing rashes, joint involvement with pain and swelling in the joints, photosensitivity which leads to skin reactions on exposure to the sun, hair thinning and Raynaud's syndrome, where the fingers and toes change color on exposure to cold temperatures or stress.

## What causes SLE ?

- There is no one cause of SLE that has been identified, but several factors have been implicated as culprits.
- Genetics play an important role in the development of SLE. Research has shown that there may be a genetic link. Lupus does run in families, but no single gene has been identified. There may be multiple genes involved which play a role in the development of SLE.
- Environmental factors are also thought to contribute to the development of SLE. Infectious causes such as bacteria or viruses have been suggested, though no pathogen has been consistently identified or linked with the disease.
- Hormones are also thought to be important in SLE. The X chromosome (women have 2 X chromosomes, men have 1), and the female hormone estrogen are thought to be important in causing disease susceptibility.

## SLE and women

- Women with lupus deal not only with the disease, but specific aspects of life that lupus can affect, by disease activity itself, and also due to effects of medications.
- Lupus can present itself at any age, and can have different effects at different ages.
- Although there are several medications available to treat lupus, and the overall prognosis of the disease has significantly improved through the years, women with lupus are at higher risk for developing conditions such as osteoporosis or bone loss, heart disease, depression and fertility problems.

## SLE and women

- Lupus can affect women of any age and can impact various aspects of life, as well as lead to long term sequelae of disease.
- Childhood and teenage years/ puberty – growth, body image issues, bone formation.
- The 20s – contraception, fertility, bone formation.
- The 30s – fertility, later pregnancies, early menopause.
- The 40s – early menopause, bone loss/ osteoporosis
- The 50s – menopause, osteoporosis, cancer

## More than just SLE ?

- Growth
- Depression/ body image issues
- Immunizations/ risk of infections
- Fertility
- Osteoporosis
- CV risk
- Fibromyalgia/ chronic fatigue syndrome

## Childhood and puberty

- SLE may present itself in pre-pubertal and pubertal years.
- Physical stress of a chronic illness such as SLE can delay the onset of puberty.
- Skin manifestations such as rashes, hair loss may contribute to body image issues in teenage girls.
- Medications such as prednisone can cause significant weight gain, adding to the stress of dealing with the disease.
- Prednisone can also affect bone formation, leading to lower bone strength.
- Immunizations – HPV vaccine.

## Teenage years and the 20s

- Body image issues – rashes, hair thinning, photosensitivity, weight changes.
- Medications such as prednisone can affect bone formation and strength.
- Medications such as cyclophosphamide (used for severe kidney disease) have long term effects on the development and function of the ovaries.
- Contraception is an important issue in women with lupus.
- Depression/ fatigue/ stress are important factors and are seen in higher frequencies in women with SLE as compared to their counterparts without lupus.

## The 30s

- Fertility and pregnancy are the one of the biggest concerns in women in their 30s.
- Premature ovarian failure (loss of normal ovarian function before the age of 40 years) is more common in women with lupus.
- Depression/ fatigue continues to be a significant difficulty in women with SLE.

## The 40s/ 50s and beyond

- Women with lupus have higher incidence of early menopause. Medications have an effect on ovarian function as well.
- Women with SLE may go through menopause 5 – 10 years earlier than usual.
- Early menopause increases risk of osteoporosis (low bone strength).
- Women with SLE have a higher incidence of heart disease compared to their counterparts without SLE.

# Contraception

- Birth control issues are very important in women with lupus, as it is primarily a disease seen in women of child bearing age.
- It is important to address birth control in all women with SLE, including teenagers with SLE.
- The most common method of contraception is the birth control pill which works by preventing ovulation.
- Most oral contraceptive pills contain two hormones, estrogen and progesterone, that prevent normal ovulation.
- Due to the significantly higher proportion of women affected by SLE, female hormones are thought to play a role in the development of SLE.
- Changes in hormone levels may be associated with disease flares.

# Contraception

- It is important to know and understand the various available methods for birth control.
- An important factor is the presence of antibodies called the anti-phospholipid antibodies. These antibodies carry an increased risk of blood clots.
- Studies have shown that combination pills containing low dose estrogen may be safe in patients with mild lupus and no increased risk of clotting.
- Patients with increased risk of clotting should avoid estrogen containing birth control pills as they may further increase the risk of clotting.

# Contraception

- Contraceptive measures without estrogen include progestin-only pill, which is less commonly used due to the risk of breakthrough bleeding, but may be safer in women with SLE and a tendency for clotting.
- Non-pill methods for birth control include injectables, implants and IUD.
- The Depo-Provera shot is an injectable contraceptive, progestin-only. It is given by intra-muscular injection and provides contraception for upto 3 months.
- Implanon is a single rod progestin implant, inserted under the skin. It can provide contraception for upto 3 years, with return of fertility rapidly after removal.

# Contraception

- Intra-uterine devices (IUD) are an effective, long acting and reversible option for contraception. Hormonal IUDs are available which release progestin.
- Risk of infections is an important consideration in the placement of IUDs, women with SLE may be at an increased risk of genital infections.
- Barrier contraceptive methods such as diaphragms or condoms are safe options, though not as effective as some of the other measures.

# Contraception

- It is important to weigh the risks and benefits of contraception and the various available methods in every individual patient.
- Factors such as age, history of smoking and history of heart disease are important factors in choosing birth control methods, similar to women without SLE.
- Presence of anti-phospholipid antibodies is an important factor in deciding the most appropriate contraceptive method.
- When used appropriately, oral contraceptives may be beneficial in women with excess menstrual bleeding, anemia and ovarian cysts.

## What can you do?

- Know your disease. Know your risks, including risk of clotting.
- Know your options. Talk to your gynecologists about your contraception options.
- Practice safe sexual practices.
- Discuss the importance of contraception early.
- Minimize other risks such as smoking.
- Medication compliance.

## Menstrual cycle

- Menstrual irregularities are more common in women with SLE.
- Hormonal abnormalities due to increased disease activity may contribute to irregular menses.
- Use of medications such as non-steroidal anti-inflammatory drugs or steroids can contribute to excess or heavy bleeding during cycles.
- Lupus patients are also at higher risk for developing ovarian cysts, a condition fairly common in women in child bearing age.
- Lupus patients who have low platelet counts, or anti-phospholipid antibodies, are more likely to suffer from longer and heavier cycles.

## Menstrual cycle

- Anemia is common in lupus, as well as menstruating women. Lupus patients may have a higher risk of anemia compared to women without lupus.
- Medications such as cyclophosphamide may cause temporary or permanent (premature) amenorrhea (cessation of menstrual cycles), due to injury to the ovaries.
- Due to changes in hormonal levels, lupus patients are at higher risk for disease flares during the premenstrual phase of the menstrual cycle.
- Birth control pills may help with above symptoms, but need to be used with caution and when safe.

# Pregnancy

- Women with SLE can have a successful pregnancy and give birth to healthy babies.
- Lupus patients are more likely to develop pregnancy related complications as compared to the general population.
- Lupus itself does not typically affect fertility, but certain medications such as cyclophosphamide can affect a woman's ability to conceive, primarily due to their effect on the ovaries.

## Pregnancy complications

- Lupus patients are at a higher risk of pregnancy complications such as high blood pressure, kidney disease, pre-eclampsia (high blood pressure after 20 weeks of pregnancy).
- Patients on steroids for SLE have a higher risk of developing pregnancy associated diabetes.
- Pregnancy loss can occur in about one-fifth of lupus pregnancies. This risk is higher in patients with high blood pressure, active kidney disease, and presence of anti-phospholipid antibodies.
- Preterm delivery (before 37 weeks of pregnancy) is more common in patients with SLE, about one-third of patients with SLE delivery preterm. Preterm delivery is 3 times more likely in women with lupus .

## Pregnancy outcomes/ neonatal complications

- Most women with SLE give birth to health babies.
- Babies born to women with SLE have higher risk of low birth weight and intra uterine growth retardation (IUGR). This is more likely in women who are on medications such as prednisone, or have active disease.
- Babies born to patients with certain antibodies (cells) seen in lupus patients, such as anti-SSA/ anti-SSB antibodies , are at risk for developing congenital heart block. This risk is low, ~3%. Women with these antibodies need close monitoring of their baby's heartbeat with ultrasound for the heart.

## Plan your pregnancy

- Pregnancy planning is crucial.
- Lupus patients are at a risk of flare of their disease during and after pregnancy and delivery.
- For best outcomes for both the mother and the baby, pregnancy planning is recommended when lupus has been quiet or in remission for 6 months; this includes kidney disease.
- Medications that are harmful to the baby should ideally be discontinued when possible.
- Disease flares may present as symptoms such as joint pain or rashes.
- Patients with kidney disease may have flares involving their kidneys and may need medications to treat the lupus flare.

# Pregnancy management

- Monitoring during pregnancy is vital. Pre-natal care is extremely important to ensure the outcomes for both the mother and the baby.
- Women with lupus should establish care with a high-risk obstetrician, along with following closely with their rheumatologist.
- Mothers should be assessed for disease activity at least once every trimester, and more often if there is concern over active disease.
- Blood tests and urine tests measuring disease activity should be performed as soon as pregnancy is determined, and followed periodically throughout the pregnancy depending on disease activity.

## Treatment recommendations

- Medications that may harm the baby are avoided during pregnancy, while those medications considered relatively safe are continued to avoid lupus flares.
- Lupus flares during pregnancy need to be managed considering both the mother and the baby. Certain medications used to treat severe flares, such as kidney disease, are harmful for the baby. Decisions are made on an individual basis after weighing the risks and benefits of all options.
- Many patients with lupus are able to have a successful normal vaginal delivery, but c-section may be necessary if the mother or/ and baby are under stress.

## Breast feeding

- Most women with lupus are able to breast-feed their babies.
- If the baby is born prematurely, the baby may need supportive care in the hospital, or may not be strong enough to draw milk. Using a breast pump may be helpful to express milk till the baby is strong and healthy enough.
- At times the mother may be unable to express adequate amounts of milk. In such scenarios, nutritional support for the baby is important for its growth.
- Some medications may transfer through the breast milk to the baby. Women who are breast feeding should review their medications for safety and recommendations.

## What can you do ?

- Establish care with a high risk obstetrician and continue close follow up with your rheumatologist.
- Pay attention to your pre-natal care. Pay attention to your diet, nutrition, exercise (yoga).
- Talk to your doctors about which medications are best for you during your pregnancy.
- Follow up with your doctor post delivery. This is also a time for risk of disease flare, as your body transitions back into its non-pregnant state.
- Discuss and consider options for birth control. Breast feeding is not a reliable method of birth control.
- Consult your doctor to know which medications you can safely take when you are breast feeding.

# Menopause

- Patients with SLE are at a risk of early menopause by upto 5-10 years.
- Menopause may or may not be associated with decrease in the signs and symptoms of SLE.
- Estrogen containing hormone replacement therapy has been associated with an increased risk of lupus disease activity and flares, though minimal.
- Risks and benefits of such therapy should be carefully weighed on an individual basis.
- Estrogen therapy is not recommended in lupus patients with anti-phospholipid antibodies who are at an increased risk of clotting.

## Skin protection

- Approximately two-thirds of people with lupus develop some form of skin involvement. Skin involvement may be seen in the form of different types of rashes, with or without sensitivity to the sun.
- Certain types of skin rashes are seen more commonly in sun exposed areas, such as the face, neck, arms and upper chest.
- Patients with lupus may also suffer from photosensitivity – sensitive skin to the sun leading to skin irritation and rashes.
- About 40-70% patients with SLE experience worsening of disease on exposure to UV rays from sunlight or artificial light.

## What can you do ?

- Skin protection plays an important role in management of skin disease.
- Preventative measures such as use of adequate sunscreen are very important.
- Sunscreen with SPF of 30 or higher is recommended, with repeated use as needed.
- Avoid prolonged exposures to the sun.
- Avoid being outdoors between the times of 10 am to 4 pm.
- Wear sun protective clothing and broad rimmed hats.
- Patients with eye sensitivity should invest in a pair of sunglasses.

# Osteoporosis

- Osteoporosis is a condition resulting from bone loss in which the bones become fragile and are more likely to fracture.
- Women have a higher risk of osteoporosis. Of the estimated 10 million Americans with osteoporosis, 8 million or 80% are women.
- Approximately 1 in 2 women over the age of 50 will break a bone due to osteoporosis.
- Women can lose upto ~20% of their bone mass in 5-7 years following menopause.
- Risk factors for developing osteoporosis include female gender, older age, smoking, alcohol consumption, family history, low weight and medications.

# Osteoporosis

- Women with lupus are at a higher risk of osteoporosis due to several reasons.
- Inflammation from active lupus increases the risk of bone loss.
- Menopause can occur up to 5-10 years earlier in women with lupus, increasing the life time risk of a fracture due to bone loss.
- Medications such as prednisone are harmful to the bone and contribute to bone loss increasing the risk of fracture.
- Teenagers and young adults with active lupus or who are on medications, often do not reach a high bone mass or strength, and are more susceptible to fractures later on.

## What can you do ?

- Healthy lifestyle is important in prevention of osteoporosis. Do not smoke or drink.
- Exercise regularly. Weight bearing exercises are very important for building and maintaining bone strength.
- Ensure appropriate nutrition. Calcium and vitamin D are essential for bone health. Ensure adequate amounts in your diet. Talk to your doctor about supplementation if needed.
- Exercise, nutritious diet with calcium and vitamin D are vital if you are on prednisone.
- Fall prevention is key. Stronger muscles and better balance help with fall prevention. Make your house fall proof.
- Get yourself screened for osteoporosis.
- Talk to your doctor about treatment and medication options.

# Cardiovascular disease

- Women with lupus have a significantly higher risk of developing heart disease.
- Under-40 lupus patients are 6 times more likely to develop heart disease as compared to people without lupus.
- Risk of cardiovascular disease is increased due to several reasons including lupus itself. Chronic inflammation leads to plaque build up and higher risk of cardiovascular disease.
- Lupus patients are more likely to suffer from high blood pressure and high cholesterol, which in turn increases the risk of heart disease.
- Medications such as prednisone can also increase the risk of high blood pressure, high cholesterol as well as diabetes, risks for heart disease.

## What can you do ?

- Follow a healthy life style. Do not smoke. Avoid excess alcohol consumption (no more than one drink a night).
- Follow a healthy nutritious diet. Fruits, vegetables, whole grain, fish (twice a week) is encouraged. Limit salt intake. Choose foods low in cholesterol and saturated and trans fats .
- Exercise regularly.
- Maintain a health weight.
- Follow with your doctor regularly to monitor your blood pressure and cholesterol.
- Know the signs of heart attack or stroke; seek medical attention immediately.

## Fibromyalgia/ Chronic fatigue

- Fibromyalgia is a condition causing chronic wide spread pain and tenderness in joints, muscles and soft tissues. It has been linked to fatigue, sleep problems, depression and anxiety.
- Patients with lupus are more likely to suffer from fibromyalgia. Diagnosis is made clinically based on symptoms.
- Both conditions are characterized by disease flares and remissions.
- Chronic fatigue is commonly associated with both conditions. 90-95% of lupus patients experience significant fatigue at some point in their disease, some patients may have chronic fatigue.
- Treatment of fibromyalgia is different from treatment of lupus.

## What can you do ?

- Lifestyle changes are an important part of management of fibromyalgia/ chronic fatigue.
- Exercise is extremely important. Low impact aerobic exercise such as walking, stationary bike or water exercises are encouraged.
- Stay active, but know your limitations.
- Maintain your sleep hygiene. Go to bed and wake up at the same time everyday.
- If you wake up tired, or wake up multiple times at night, talk to your doctor about a sleep study.
- Get organized. Write down your goals, aims, list of chores, etc.
- Talk to your doctor about medications to help with your fibromyalgia pain.

# Depression

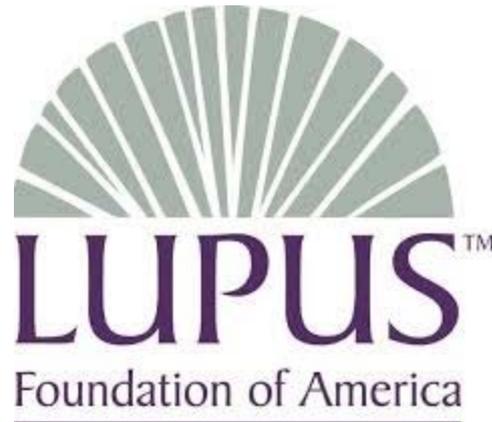
- Living with lupus is stressful. People with a chronic illness such as lupus are at a higher risk of depression.
- Upto 60% of people with a chronic illness will suffer from depression at some point in their life.
- Unpredictable nature of lupus, possibility of disease flares can lead to anxiety; patients with lupus may hesitate making plans leading to a feeling of isolation.
- Symptoms such as low energy, skin rashes, pain, along with medication effects can contribute to depression in SLE.
- Depression in turn may worsen symptoms of pain, fatigue, poor sleep and low energy.

## What can you do ?

- Talk to your doctor about how you feel. Get evaluated for possible depression.
- Discuss options for treatment such as psychotherapy, counseling, medications, yoga and exercise.
- Understand your lupus, talk to your doctor about best managing your lupus. Stay educated.
- Avoid negative self-thought, keep your thoughts positive.
- Take it one day at a time.
- Be as active as you can, keep up health living habits; sleep hygiene, exercise, well balanced diet.
- Follow activities that make you feel better; short walk, cooking, gardening, call a friend.
- Keep your support network close. See a therapist if needed.

## Support groups

- Expand your circle
- Reach out to other people with SLE.
- Lupus Foundation of America, Philadelphia Tri-State Chapter



## Take home points

- In the 1950s, most people diagnosed with SLE lived fewer than five years. Today, over 90% now survive for more than ten years, and many live relatively asymptotically. 80-90% can expect to live a normal lifespan.
- Though there is no known “cure” for lupus, it is treatable. The goal of therapy is to control symptoms effectively to enable a relatively normal life.
- Lupus predominantly affects women, especially young women and those in the child bearing ages, which leads to certain unique challenges.

## Take home points

- Education and awareness of the possible challenges is important.
- Appropriate planning for contraception and pregnancy can significantly decrease complications and improve health outcomes for both mothers and babies.
- Preventive care is extremely important. Managing risk factors for bone loss, high blood pressure and heart disease can help decrease the risk of developing these conditions.
- Depression, fatigue and fibromyalgia are seen in higher rates in women with lupus. Recognition of the symptoms, life style changes and a support network is important.
- There is a lot of ongoing research (new medication approved after >50 years), with hopefully a “cure” somewhere on the horizon.

THANK YOU

QUESTIONS ?

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