We hope this leaflet will help you understand a little more about this condition. If you have any further questions, please do not hesitate to ask the nursing or medical staff. They will be happy to help you.

What is Mycosis Fungoides?

- Mycosis fungoides is a skin disease caused by cells from your immune system collecting in the skin.
- These cells are called T-lymphocytes and are one type of the white cells in your blood that help fight infection.
- Many of these lymphocytes in your skin are abnormal and their presence causes the changes that you have noticed.
- Mycosis Fungoides is the most common form of Cutaneous T-cell Lymphoma. Cutaneous Lymphoma is however rare, affecting 6 per million people per year.
- In most people, these abnormal lymphocytes only build up in the skin. Other parts of the body are only affected in rare cases.
- When seen in the skin, it most commonly looks like a faint, dry, red rash, like mild eczema or psoriasis. Occasionally the skin may become more red and lumpy.

What kind of treatment can I expect?

- Treatment aims mainly to reduce the abnormal appearance of the skin and to control any itching or other symptoms you may have.
- The most common treatments are the use of steroid creams, moisturisers and ultraviolet light (UVB or PUVA).
- If the disease causes the skin to become very thick in places then radiotherapy can be used as a form of treatment. This treatment would be done by a specialist called a radiotherapist.
- A new tablet treatment called Bexarotene related to vitamin A is undergoing trial.
- Your doctor may also want to assess how much you are affected by the Mycosis Fungoides. This will involve a full examination and investigations such as blood tests and scans. Your doctor will discuss these with you.

Risks and complications of treatment

If a specific treatment has been offered, then please read the information leaflet relevant to that treatment. The doctor will discuss any risks or complications associated with this treatment with you. If you have any questions please feel free to ask.

Will I get further problems?

- Most people with Mycosis Fungoides have some areas of flat, red, slightly scaly skin. Which usually affects the lower trunk but can be more wide spread.
- These areas of skin may itch from time to time change very little over a lifetime.
- Sometimes the skin becomes thicker, such that it can be easily felt, and is known as a “plaque”.
- A small number of people will go on to get areas of considerable thickening of the skin. These swellings are called tumours.
- If you develop tumours of Mycosis Fungoides, the disease may spread and affect places other than your skin, such as the lymph glands.
The surface of tumours may be lost leaving areas of broken skin called ulcers.

**What do I do now?**

- For the next few years it is likely that you will attend follow-up clinics at hospital and receive treatment to meet your specific needs.

**Can I do anything to prevent it from becoming worse?**

- There is no obvious cause of Mycosis Fungoides and it does not appear to be influenced by diet or medication.

- Natural sunshine can suppress the condition but it must be used with caution as high light exposure to sunlight can cause skin cancer.

Protecting yourself from strong sunshine will help prevent your skin from ageing and should reduce the chances of you developing wrinkles, brown marks, Actinic Keratoses and Skin cancers.

Protection from sunshine means:

- **S**tay in the shade 11am - 3pm
  The sun is most dangerous in the middle of the day-find shade under umbrellas, trees, canopies or indoors

- **M**ake sure you never burn
  Sunburn can double your risk of skin cancer

- **A**lways cover up
  Sunscreen is not enough-wear a t'shirt, a wide brimmed hat and wraparound sunglasses

- **R**emember to take extra care with children
  Young skin is delicate, keep babies out of the sun around midday

- **T**hen use factor 30+ sunscreen
  Apply sunscreen generously 15-30 minutes before you go outside and reapply often.

Also report mole changes or unusual skin growths promptly to your doctor.

**If you have any questions**

Please do not hesitate to ask any questions. You can ask a member of the nursing or medical staff, or call us the Skin Cancer Nurse Specialist Karen Curtis on 01823 344956.