

LIVING WELL WITH CLL NURSE SPECIALIST PERSPECTIVE SUPPORTIVE RESOURCES

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Background

- Role of CLL nurse specialist started in June 2012
- Nottingham University Hospitals were the first to employ a nurse specialist specifically for patients with CLL/SLL
- Specific CLL clinic with a nurse led clinic running alongside doctors . One of the first trusts in the country to have a CLL MDT which meet every two weeks

Your Keyworker

- Anyone who has a diagnosis of CLL should be allocated a keyworker
- Your Keyworker should be easily accessible, approachable and be able to signpost to relevant resources and services when appropriate.

Diagnosis

- Often an incidental finding with no symptoms, feel well
- How you are told your diagnosis is important, often a long wait from seeing your GP to seeing a Consultant
- Good understanding from the start, can improve how you deal with what this means to you and your family.
- How to cope with a chronic, incurable disease

- Information can be tailored to what you want to know and when
- ‘Chronic’ meaning slow, there is time to step back and learn at your own pace
- Discussions backed up with written information to take away and read at home
- Time given to ask questions- ‘No such thing as a silly question!’
- Appointments can be far apart. Nurse Specialist always there in between as point of contact

Aim as a Nurse Specialist

- To provide you with as much information as you want, when you want it
- To be a point of contact whenever you feel you need to talk to someone, clarify or ask questions
- To feel there is always someone there for you. You are not bothering them, there is always time to talk
- Make you feel empowered, well informed and in control of your life
- Act as an advocate

Make the most of your medical team

- Communicate with the doctors and nurses. If you haven't told us, we can't help. There maybe something we can do
- Good Communication is a good cornerstone for 'living well with CLL'
- Write down questions when you think of them and bring them with you
- Bring a trusted friend/relative with you, an extra pair of ears can help remember more

Watch and Wait

- Sometimes difficult to deal with 'Watch and Worry'
- Chronic disease that may not require treatment
- Ensure aware of possible B symptoms and what to do should you feel you have any
- Contact numbers, who to call when
- Communication with your GP

Treatment

- Treatment options greatly changed over the last few years
- FCR remains gold standard treatment for fit/well patients, but now lots more options
- Sometimes decision more difficult due to increased choice
- Many trials available- what does this involve
- Nurse there to support during decision making, to ensure informed choice
- Newer drugs are taken for unknown period of time

Holistic Needs Assessment

- The HNA and care plan is aimed to ensure that people's physical, emotional and social needs are met in a timely and appropriate way, and that resources are targeted to those who need them most. The information gathered from an HNA can also be shared with the multidisciplinary team (MDT) to improve a persons management and care and the data collected can influence commissioning of future services
- Personalised care planning to move away from one size fits all

HNA's

- **Physical concerns-** tired/exhausted/fatigue, pain, memory, concentration, sexuality
- **Practical concerns-** caring responsibilities, work and education, money/housing, insurance and travel
- **Family/relationship concerns-** partner, children, relatives, friends
- **Emotional concerns-** Loneliness, isolation, sadness and depression, spiritual or religious concerns
- **Lifestyle or Information needs-** Support groups, exercise and activity, smoking, alcohol, drugs, sun protection, hobbies

Possible concerns

- Family – is this hereditary?
- Insurance – critical illness/life/mortgage
- Work – risk of infection, do I need to tell them
- Travel – can I travel abroad, insurance
- Dealing with anxiety/uncertainty
- Possible treatment
- Symptoms

Living well with CLL

- Gain a good relationship with your medical team
- Feel confident to talk to them, and ask questions
- Feel able to contact your keyworker anytime- No such thing as a silly question!
- Feel you have all the information you want, but able to ask for more if needed
- Feel in control and able to carry on with your life, feel positive and plan for the future

Living well with CLL

- Be aware of increased risk of infections, may need a lower threshold if symptoms persist
- Ensure up to date with vaccinations –Flu, pneumonia, NOT shingles

Other supportive resources

- The internet is good but sometimes too much information that is not relevant to you
- On line community, to talk to other people with CLL
- CLL Forum
- CLLSA
- Lymphoma Association
- Bloodwise
- Macmillan
- Cancer Research
- All can offer valuable support and information alongside your medical team



**THANK
YOU!**