

Macmillan Greater Manchester Lymphoedema Guidelines to provide personalised care

Purpose of this document: To provide guidelines to lymphoedema practitioners and specialists to ensure people with lymphoedema have personalised care. To empower them to self-manage through education, information and sign posting. These guidelines aim to standardise patient care across Greater Manchester.

Exclusions: This paper relates to Adult Patients only. Children, Teenage Lymphoedema patients should be managed in accordance with normal protocol.

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Introduction

These guidelines have been developed by patients, carers and lymphoedema practitioners that have been affected by lymphoedema, or work in the area of lymphoedema. It is understood that individual differences and the diversity of patients that make up the lymphoedema population, differ from person to person. Tailoring information to a patient needs will be of the greatest benefit to patients, it can empower them to self-manage their lymphoedema away from the lymphoedema service.

Key Message

A personalised approach is paramount to a patient care, this will allow for the different needs that lymphoedema patients have. To ensure standardisation across Greater Manchester there are certain criteria that are recommended to always be included in a care plan. It is recognised that a care plan template may not be suitable for all patients, a set of guidelines however is essential to ensure consistency across Greater Manchester.

Principles of a Lymphoedema Care Plan

Information and parts of a care plan can be provided in stages. This would ensure that people receive the information in an appropriate format and at a suitable time during treatment.

It is essential that information is written down and personalised so the person is able to take the information away, ensuring they have understood what has been provided.

The below principles are recommended to be included in a care plan. The lymphoedema practitioner should decide what information should be provided and when based on the patients need.

Principles	Criteria
Lymphoedema type	Mild lymphoedema – usually managed with exercise, skin care and a compression stocking or sleeve. Moderate or severe lymphoedema – usually requires complex lymphoedema therapy (CLT). Less commonly you may have laser treatment, lymph taping and surgery.
How they developed lymphoedema	Primary/Secondary or advise if unknown
When diagnosed with lymphoedema	
Other conditions	How lymphoedema may affect other health conditions and what they need to be aware of to ensure their lymphoedema is not affected
Next Appointment date	
When they might be discharged	If possible, to help the patient understand the length of time it may take to get their condition reduced and stable. Number of appointments they might expect to have



Principles	Criteria
Getting to know your patient - what matters to them	<p>6 Questions you could ask you patient to understand them:</p> <ol style="list-style-type: none"> 1. Who are the most important people in your life? How often do you see them and what do you like to do together? (This could be partners, family, friends or even pets!) 2. What would make a good day for you?(Think about all the elements that would make up a good day, like who you would be with and what you would do.) 3. When you are having a bad day what can help to make it better? (think about the things that you or others can do to help you if you are having a bad day) 4. What are the daily or weekly things you enjoy doing? (Think about the important activities and routines that you have) 5. What would you never leave home without? (Think about the important possessions you have and always like to have with you) 6. What do you think the people who know you well would say your best qualities are? (for example, sense of humour, honesty, loyal friend, kind and caring)
Exercise	<ul style="list-style-type: none"> • LSN pictures how to exercise • when to wear garment for exercise • garment wearing and swimming • relaxation techniques • Types of exercise depending on person (can they still play their sport, how to embed exercise into your day) <p>Sign post to websites, exercise referral schemes Or look at Social Prescribing within the locality</p>
Skin Care	<p>LSN Videos Before or after putting hosiery on Types of creams/Emollient Morning and night Bathing (wash) of legs and wounds daily Techniques in how to moisturise</p>
Dressings for wound care	Changing of dressings to suit each leg (daily or more?)
Simple Lymphatic Drainage	Technique on how to do this
Hosiery	<p>Apparatus to help with applying hosiery Wraps to be worn as often as is possible (daily)</p>

Principles	Criteria
Pain	What is lymphoedema pain, what is other pain from other conditions? What is normal for that person?
Weight management	Reduces impact of lymphoedema and worsening of lymphoedema. Provide information or plan to refer into weight management service
When they should seek immediate help	Cellulitis – what to look for, information to discuss with GP BLS/LSN - https://www.thebls.com/documents-library/consensus-document-on-the-management-of-cellulitis-in-lymphoedema
Emotional wellbeing	Support Group signposting Other support websites are attached to this guidance
Friends and family	Information that can be shared about lymphoedema prevention. Including primary lymphoedema, if there is a hereditary risk of developing lymphoedema.
People involved in your care	Who will be involved in the patients care What they need to share with other health professionals about their lymphoedema
Goal setting (SMART - Specific, Measureable, Achievable, Relevant, Time based)	Asking patient if there are goals they want to set to help them self-manage e.g. start exercising, increase amount of time they spend exercising Appropriate/ Relevant to the individual
Massage machines	Loaning and buying
Practicalities of lymphoedema	Specialist socks, slippers, shoes etc. can be purchased
Hints and Tips	Hints and tips Elevating legs Avoid scratching legs Gardening - gardening gloves, long sleeves Insect bite creams

Resources for people living with lymphoedema

Organisation	Site Link
Lymphoedema Support Network	https://www.lymphoedema.org/
British Lymphology Society	https://www.thebls.com/
Cancer Research – exercise and lymphoedema	https://www.cancerresearchuk.org/about-cancer/coping/physically/lymphoedema-and-cancer/treating/exercise
Cancer Research – skin care and lymphoedema	https://www.cancerresearchuk.org/about-cancer/coping/physically/lymphoedema-and-cancer/treating/caring-for-your-skin
Macmillan Cancer – Understanding Lymphoedema booklet	http://be.macmillan.org.uk/Downloads/CancerInformation/CancerTypes/MAC11651E15NLymphoedema.pdf
Lymph Connect	https://www.lymphconnect.co.uk/lymphconnect.html
NHS - lymphoedema	https://www.nhs.uk/conditions/lymphoedema
Every Mind Matters	https://www.nhs.uk/oneyou/every-mind-matters/your-mind-plan-quiz/
NHS – Weight loss plan	https://www.nhs.uk/live-well/healthy-weight/start-the-nhs-weight-loss-plan/



Up to 1 in 4 people will experience a mental health problem at some point in their life time. If you need some support, these services can help.

Organisation	Description	Area	Website link
Self Help	Support for anyone experiencing common mental health problems. Available to anyone who is registered with a GP in Manchester or Stockport, and is aged 18 and over	Manchester Stockport	https://www.selfhelpservices.org.uk/referrals/
Six Degrees Social Enterprise	Help for people experiencing common mental health problems, who live in Salford aged 16 and over. Contact your local GP who can refer you	Salford	http://six-degrees.org.uk/about-us/
The Big Life Group	A wide range of services across Greater Manchester, Big Life helps you look at everything affecting your wellbeing	Across Greater Manchester	https://www.thebiglifegroup.com/search/talking+therapies/
Primary Care Psychological Therapy Service	Work with people to help address a range of problems they might be experiencing. Provides free, confidential talking therapies for adults aged 16 years and over.	Bolton	https://www.gmmh.nhs.uk/bolton-psychological-therapy-service
Trafford Psychological Therapies	Provide talking therapies for those experiencing difficulties with anxiety and depression. Contact your local GP who can refer you or you can refer yourself.	Trafford	https://www.gmmh.nhs.uk/tpt
Healthy Minds	Provide a range of treatment and support for people with any of the common mental health problems. If you're over the age of 16 years and registered with a GP in these boroughs then you can refer yourself through the online form.	Oldham Bury Stockport Tameside Glossop	https://www.penninecare.nhs.uk/healthyminds
Thinking Ahead	Help with everyday issues that affect your mental wellbeing, such as anxiety and depression. If you live in Heywood, Middleton or Rochdale and are over the age of 16.	Heywood Middleton Rochdale	https://www.thebiglifegroup.com/service/thinkingahead/
Think Wellbeing Wigan	For people with long term physical health conditions experiencing low mood, anxiety or depression. For people registered with a Wigan GP and age 16 and over. You can refer yourself	Wigan	https://www.nwbh.nhs.uk/think-wellbeing-wigan



Resources that may also support practitioners in the development of a patient care plan.

Organisation	Description	Website link
NHS Highland	Lymphoedema Diagnosis, Treatment and Care-Home Page	https://tam.nhsh.scot/home/therapeutic-guidelines/lymphoedema/lymphoedema-diagnosis-treatment-and-care-home-page/
Airedale NHS Foundation Trust	What to Expect from the Lymphoedema Service – Patient Information Leaflet	http://www.airedale-trust.nhs.uk/wp/wp-content/uploads/2013/10/Lymphoedema-Service-What-to-expect.pdf
NHS	Toolkit for producing patient information	https://www.uea.ac.uk/documents/746480/2855738/Toolkit_for_producing_patient_information.pdf
NHS Oxleas	How to write a good care plan.	http://oxleas.nhs.uk/site-media/cms-downloads/Writing_Good_Care_Plans_Oxleas.pdf

