A GUIDE FOR COMMUNITY HEALTH PROMOTERS

Lumps and Swellings of the Arms and Legs

How to notice them early, and how to help the patient reach the right care



Notice. Send. Stay.

Dr. Nicholas Okumu

A companion to Early Detection of Musculoskeletal Sarcomas: A Guide for Primary Healthcare Workers

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Community Health Promoters and those who train and supervise them may freely photocopy two pages of this guide for their work: "Your record of referrals" and "The guide on one page".

For permission requests, contact Dr. Nicholas Okumu at nicholas.okumu@live.com.

Acknowledgements

This guide is for the Community Health Promoters of Kenya. You are the ones who visit the home, who notice what others miss, and who can walk with a family until they reach the right care. I thank you for that work.

I thank Dr. Mohammed Ezzi and Dr. Solomon Kanyago, my co-authors on the study of osteosarcoma at Kenyatta National Hospital. What we learned from those patients is the reason this guide was written.

I am grateful to the patients and families who came to us, many of them late and after a long road. This guide is an attempt to shorten that road for those who come after them.

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Why this guide was written

Some lumps and swellings of the arms and legs are cancers of the bone or of the soft tissues such as muscle and fat. These cancers are rare. They can be treated, and the limb can often be saved when the patient reaches a specialist early.

In Kenya most patients reach the specialist late.

What we found at Kenyatta National Hospital in patients with bone cancer

Half of the patients had lived with their symptoms for six months or more before the cancer was found.

Nearly 6 in every 10 already had cancer that had spread, most often to the lungs.

Of the 54 patients who had surgery, 52 lost the limb.

A study from western Kenya looked at where the time is lost for children with cancer. Families took the child to a health worker about one month after the illness began. The longer delay came afterwards, between that first visit and the correct diagnosis. It lasted more than three months.

This means patients are not lost because nobody saw them. They are lost between one health facility and the next. They are told to come back later, or they are sent somewhere and do not know how to get there, or the money runs out, and they go home.

You are the person who visits that home. You can notice the lump, and you can walk with the patient until they have been seen by the right person.

Your work has three parts

1. Notice. Find the person with a lump, swelling or bone pain that is not going away.

2. Send. Refer them to the health facility the same week.

3. Stay. Follow the patient through every step until a specialist has seen them, and help them when they get stuck.

You are not asked to decide what the lump is. Most lumps are not cancer. Only tests at the hospital can tell.

Part 1. What to look for

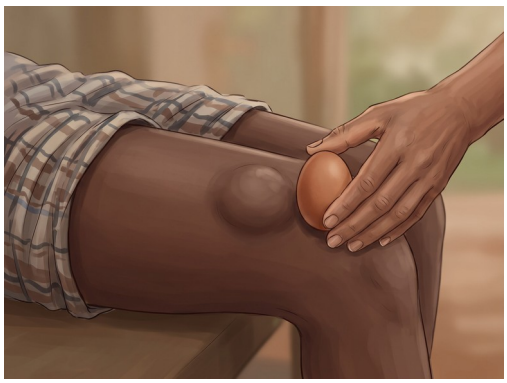
Ask about lumps, swellings and bone pain during your household visits. Look at the arm or leg and compare it with the other side.



Look at both sides together. One knee is swollen, the other is normal.

Send the person to the health facility if you find any of these

- A lump or swelling on an arm or leg that has been there for **more than 4 weeks**.
- A lump that is **as big as a chicken egg or bigger**.
- A lump that is **getting bigger**.
- A lump that is **deep and does not move** when you push the skin over it.
- A lump that has **come back** after it was removed.
- Pain in a bone that has lasted **more than 2 to 3 weeks**, above all pain that is worse at night or wakes the person from sleep.
- A child or teenager who is **limping** and nobody can say why.
- A bone that **breaks after a small fall**, or with no fall at all.
- A swelling that has **not gone away after treatment**, for example after a course of antibiotics.



A lump as big as a chicken egg, or bigger, must be checked.



Bone pain that is worse at night or wakes a child from sleep must be checked.

Remember

The lump does not need to be painful. Many dangerous lumps do not hurt at first.

A lump that appeared after a fall still needs checking. Often the fall only makes the family notice a lump that was already there.

These problems can happen at any age. Bone cancer is seen most in older children and teenagers.

What not to do



Do not massage a lump or swelling, and do not apply oil or herbs.

- Do not massage the lump, and tell the family not to.
- Do not let anyone cut it, drain it or apply herbs to it.
- Do not tell the family to wait and see.
- Do not tell the family it is cancer. You cannot know, and neither can they.

Part 2. What to do when you find one



Fill in the referral form and explain it to the family.

1. **Refer the same week.** Send the person to your link facility. Use your referral form (MOH 100) and record the referral on your phone if you use the electronic Community Health Information System.
2. **Write down three things** for the clinician: when the lump or pain started, whether it is growing, and what treatment has been tried.
3. **Explain it simply to the family.** You can say: "This has lasted too long and needs to be examined at the facility. Most lumps are not serious, but this one must be checked."
4. **Tell your Community Health Assistant** that you have referred this person.
5. **Agree a day** when you will come back to hear what happened. Make it within one week.

Part 3. Walking with the patient

This is the most important part of your work. A referral form is only the beginning. Your task is to make sure the patient arrives at each step and is not sent home without an answer.



Your task is to see that the patient reaches each step.

The journey

Step	Where	What should happen	What you do
1	Your link facility (dispensary or health centre)	A clinician examines the patient and sends them for an X-ray or an ultrasound scan, or refers them to a hospital.	Check that the patient went. If they were told to wait and the lump or pain is still there after 2 to 3 weeks, send them back and ask the clinician for a referral.
2	A hospital with X-ray and ultrasound (sub-county or county hospital)	An X-ray for bone pain or a hard swelling. An ultrasound scan for a soft lump. If the result is worrying, the hospital writes a referral letter to a specialist.	Help the family plan the trip. Remind them to keep every film, report and letter. Ask what they were told and when the next visit is. If the X-ray is normal but the pain or swelling continues, send them back.
3	A specialist team (Kenyatta National Hospital in Nairobi or Moi Teaching and Referral Hospital in Eldoret)	More tests, which may include a scan and a small sample taken from the lump. Then the team explains the treatment.	Prepare the family for several visits. Keep following until the specialist has seen the patient, and keep supporting them through treatment.

One warning to pass on to the family

If someone at a small facility offers to cut the lump out or take a sample before a specialist has seen the patient, the family should ask to be referred first. A lump that is cut out without a plan is more likely to grow back, and the chance to save the limb may be lost.

What the patient should carry to every visit



☐ National identity card. For a child, the birth certificate or birth notification.

☐ Social Health Authority (SHA) registration details.

☐ The referral form or referral letter.

☐ All X-ray films, scan reports and laboratory results. Never leave the films behind.

☐ A list of the medicines and treatments already tried.

☐ Your phone number, and the phone number of a relative.

☐ Money for transport and food. A relative to accompany the patient if possible.

Helping with the cost

Cancer treatment is covered by the Social Health Authority. In May 2026 the cover for cancer was raised to as much as KSh 800,000 a year. To use it, the family must be registered, and the patient must be referred upwards from a primary health facility.

- Check that the family is registered with SHA. They can register by dialling *147# on a phone.
- Make sure the patient leaves each facility with a referral letter to the next one.

Following up

- **Within one week of the referral:** visit or call. Did they go? What were they told? What is the date of the next visit?
- **If they did not go:** ask why, without blame. The usual reasons are money, fear, not knowing where to go, or trying a traditional healer first. Help to solve the reason, and tell your Community Health Assistant.
- **Before each visit:** remind the family of the date and of what to carry.
- **After each visit:** ask what happened and write it in your record.
- **During treatment:** many patients stop before the treatment is finished. Keep visiting and keep encouraging them to attend.

When you are stuck

If the patient has been sent home without an answer, if a facility will not refer, or if you do not know where to send them next, ask for help.

Dr. Nicholas Okumu: phone 0720 797450, email nicholas.okumu@live.com

Say who you are, where you work, the age of the patient, what you have seen and how long it has been there.

Part 4. Questions families ask



Is it cancer?

I cannot tell, and nobody can tell by looking. Only tests at the hospital can show what it is. Most lumps are not cancer, but this one has lasted too long and must be checked.

It started after a fall. Is it not just the injury?

An injury should get better in two to three weeks. If the swelling or pain is still there, or is getting worse, something else may be wrong and it needs to be examined.

Can we try herbs or massage first?

Please go to the health facility first. Massage can do harm, and every week of waiting makes treatment harder.

Is it witchcraft or a curse?

No. It is an illness of the body, and it is treated in hospital.

Can the rest of the family catch it?

No. Cancer does not pass from one person to another.

Will they cut off the arm or leg?

The earlier the patient is seen, the better the chance of saving the limb. Patients who arrive late are the ones who most often lose it. That is why we should go now.

How will we pay?

Cancer treatment is covered by the Social Health Authority for registered families. I will help you check your registration and your referral letters.

Your record of referrals

Keep one line for each person you refer. Fill in the last columns as the patient moves through the steps.

Date referred	Name and age	What you saw	Sent to	Date you followed up	What happened

Where the facts in this guide come from

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The guide on one page

NOTICE

A lump or swelling on an arm or leg for more than 4 weeks.

A lump as big as a chicken egg, growing, deep, or one that has come back.

Bone pain for more than 2 to 3 weeks, worse at night.

A child limping for no clear reason. A bone that breaks after a small fall.

SEND

Refer to your link facility the same week, with your referral form.

No massage, no cutting, no herbs, no waiting.

Tell your Community Health Assistant.

STAY

Follow up within one week, and after every visit.

Make sure the patient carries the identity card, SHA details, referral letters and all X-ray films.

Keep going until a specialist has seen the patient.

When you are stuck, contact Dr. Nicholas Okumu: phone 0720 797450, email nicholas.okumu@live.com.

ABOUT THIS GUIDE

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A Guide for Community Health Promoters

Some lumps and swellings of the arms and legs are cancers of the bone or of the soft tissues. They can be treated, and the limb can often be saved when the patient reaches a specialist early. In Kenya most patients reach the specialist late.

Patients are not lost because nobody saw them. They are lost between one health facility and the next.

This guide shows Community Health Promoters what to look for during household visits, what to do when they find it, and how to walk with the patient until a specialist has seen them.

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