Cording

SELF ASSESSMENT GUIDE

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For breast cancer survivors who need help to regain great arm movement.

“Why is it so tight under my armpit?”

“Why is it so painful?”

“I feel like there is a band across my chest.”

“I can feel tight strings at my elbow.”

“There is a tight vertical band under my breast.”

“Why am I feeling a stinging, pulling pain in my arm when I reach out?”

“This doesn’t make any sense, the surgery was at my breast.”

“Why hasn’t my surgeon told me about treatments for this problem?”

If you have at least one of these thoughts, then you are not alone.
Cording is now recognized as a common complication after breast cancer surgery.

This e-book has been written in response to the repeated requests by women to help explain why they have difficulty with their movement and persistent pain, after breast cancer surgery.

Read about cording and go through the steps to see if you could have cording.
Then decide what steps to take to get the help you need.

Contents

Message from the author

The information contained in this book is not intended to replace a one-on-one relationship with a doctor or qualified healthcare professional. Therefore, this information is not intended as medical advice, but rather a sharing of knowledge and information based on research and experience.

Please do not do this test if your scar or surgical wound has not healed completely. For most women this may be two weeks after surgery, for some women it may take a little longer. If you have been advised to exercise your arm and raise your arm above your head and stretch the elbow back behind your body, then you should be able to progress into these tests.

If you have had surgery in the last 2-4 weeks, your treating doctor and physical therapist can and should advise about your arm exercise and stretch regime and restrictions specific to your surgery. Your exercise and stretch regime and recovery time will depend on the extent of the surgery and any post-surgical healing complications. For example, surgery that includes chest muscle dissection will have an extended recovery time in comparison with surgery that did not involve muscle dissection. Another example may be a case in which seroma forming and filling with fluid will delay the use of arm stretches and exercise and the recovery time.

If you already have a shoulder strain injury, shoulder tendon tear, or a rotator cuff injury, you should only perform this test after you have consulted your treating doctor or physical therapist.

If you have just completed radiotherapy and your skin is still really burnt, then please take a few weeks to recover before you commence this assessment. If you have had some very extensive radiotherapy and your skin is thickened and tight, then stretch gently before assessment.

This self-assessment is gentle and should not cause unmanageable pain. If unmanageable pain does occur, immediately cease the assessment and seek advice from your medical practitioner or physical therapist.

Also, just a reminder, this self- assessment guide does not allow you to diagnose cording, as diagnosis is the specific responsibility of a medical practitioner. If you ***suspect*** cording could be your problem, then contact your breast surgeon, oncologist or breast cancer team and they should assist in the diagnosis and your treatment plan.

The Cording self-assessment guide will help you:

- **know the latest physical testing for cording;**
- **know more about your body's response to surgery; and**
- **be confident to take the steps needed to get treatment that will make a difference.**

My extensive rehabilitation work with women after breast cancer has lead to me to question the standard medical beliefs about physical recovery, especially concerning surgical breast scaring and radiation damage to the skin and muscles.

This e-book will focus on cording (AWS) as it is a common complication after surgery and radiotherapy. Cording can cause temporary or permanent problems for many women.

How do you know whether you have cording? Cording cannot be diagnosed by a blood test and there is no standard scan procedure. Cording currently relies on an experienced health professional to physically assess if cording is present.

This self-assessment guide takes you through the most comprehensive physical testing for cording available. The ***Reach-Out-The-Back Test*** is a brand new test for cording assessment and is designed to better assess a wide range of cording experiences.

This guide will help you make your own movement assessment and then take action. Seek treatments to reduce pain, soften and stretch the tight tissue and recover vital shoulder movement.

What is Cording?

Cording is tightness of normal tissue within your body. The tightness develops in many women after surgery for breast cancer. It can develop in the first eight weeks during the healing phase, after chemotherapy, or after radiotherapy.

Initially, the tightness causes significant pain and can stop you from raising your arm or straighten your elbow. The tight tissue is just under the skin and can vary in thickness and presents as:

- thin strings;
- rope or cord like; or
- a really thick band of tissue.

The tight tissue extends from the breast / chest area into the arm at varying levels:

- to the armpit;
- to the upper inside arm;
- to the inside elbow;
- to the inside wrist; and
- to the trunk.

The tight tissue is thought to be part of the lymph system, which is normally fine, soft and stretchy vessels just under the skin. In this area of the body, the lymph system extends from the side of the rib cage across the armpit and then down the arm.

Cording is a complication after surgery and has mostly been linked to breast cancer surgery. Certain factors have been linked to an increased risk of developing cording. These include the extensiveness of breast surgery, being younger age, having a lower body mass index, ethnicity and healing complications. Although these factors are associated with an increased risk, the researchers offer no clear understanding about how or why cording occurs.

Therapists experienced in breast cancer rehabilitation offer an explanation – the breast scar that forms during healing attaches to nearby tissue. Initially scar tissue lacks length and stretch and may adhere to structures such as nearby lymph vessels. This can then result in a corresponding reduction in the amount of stretch at these structures.

10 days after a mastectomy, a tight band of tissue extends across to the armpit. It is so tight and painful, this woman can not move her arm above shoulder height.

CORDING

Axillary
Web
Syndrome

Cording can also be called Axillary Web Syndrome – this is usually shortened to AWS. I have chosen to use the term “cording”, because of it’s familiarity, and it aptly describes what you may be feeling.

Cording: a self-assessment guide

This guide is designed to help women who have developed pain or tightness in their breast, shoulder or arm after breast cancer surgery, chemotherapy or radiotherapy.

I have found many women:

- are anxious or worried when they feel pain in their arm;
- do not know about cording;
- are not told about the possibility of cording by their breast cancer team;
- may feel hesitant or lack confidence to ask their breast surgeon about the tight scar tissue; and
- are not sure about when normal arm movement should be expected after surgery.

If cording occurs in the weeks after breast cancer surgery, the pain and tightness can be so severe that moving the arm up to shoulder height may be impossible. This extreme tissue tightness in the armpit and extending into the arm is beyond anything we know of compared to usual wounds, sports injuries or the post- surgical response in other parts of the body. If radiotherapy is the next treatment planned, it may be physically impossible or extremely painful to get the arm away from the breast requiring radiation treatment. This can compromise cancer treatment or further increases the risk of more shoulder pain.

For less severe cases of cording during these weeks after surgery, the pain and tightness of cording still makes it impossible to fully reach the arm up or out and so makes it hard to do certain normal daily tasks.

Both of these types of cording experience add to the already high levels of stress following the diagnosis of breast cancer for both the woman and their family.

Cording that persists past 3 months, usually becomes a little less tight and less painful. However this remaining tightness can have a real impact on shoulder strength. In these cases women will report feeling pain in other parts of the shoulder and upper back.
A reduction in their level of performance of certain daily tasks will be common. Again this situation can cause increased stress, worry and pain for the woman.

Finally, there is the less obvious cording experience in the years after breast surgery- you may not be fully aware of it but it can be causing persistent and annoying shoulder or breast pain.

If you are experiencing pain and shoulder problems, then take action.

If you are experiencing pain and shoulder problems like these experiences above, or maybe in between these, then you should take action. Each of these levels of cording experience can benefit from specialized breast cancer rehabilitation support. Relying on the *wait and see* technique or arm stretches alone may not get your best outcomes.

Five reasons why Cording is not accurately assessed

1. There are no recognised accurate or reliable tests for cording. Current testing relies on skilled health professionals being able to detect cording by either seeing or feeling cording. There are also no recognized classification levels, so there is no agreement on how to describe the degree of cording.

2. Your breast cancer team may not have a health professional trained in the special rehabilitation needs for women after breast cancer and so assessment of physical impairments may be overlooked.

3. Some forms of cording may not be visually obvious to you or to your breast cancer team. Your armpit has a lot of extra skin and other soft tissues and unless it is suitably stretched, cording may be missed.

4. You could be asked to raise your arm up beside your ear, while sitting at your clinic appointment, to see if you have cording. This type of test will detect very obvious cording but will miss deeper cording at the side ribcage or side breast.

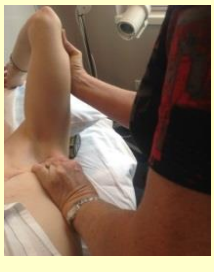
5. Sensation at the breast/chest area may be reduced post-surgery and cording may go unnoticed. An inexperienced person assessing your cording may only assess the location where you direct them to and miss the cording in the areas with less sensation.

The history

Does a lack of research interest reflect a lack of rehabilitation focus for women after breast cancer ?

Cording (AWS) was described and named in the medical literature in 2001.

A literature review in 2005 found only five studies that reported women were likely to have post surgical (breast cancer) complications which included loss of shoulder movement.



Physical treatments for women after breast cancer
In 2005 a physiotherapist reported a single casestudy of a woman with diagnosed shoulder pain after bilateral mastectomy. A review of the medical literature at the time indicated that there was no evidence available to support physiotherapy treatments for this problem.

Lymphoedema studies since the 1990's
Movement restrictions at the shoulder have been measured and recorded, yet the lack of full movement recovery by individuals or the group average was rarely commented on in these studies.

Five myths about Cording

1. Cording will go away after three months.

Untrue

While this might be true in some cases, sometimes cording remains and sometimes it develops later, after radiotherapy.

2. Cording is always thin, tight, string-like structures under the skin.

Untrue

Cording can vary and can be a very thick band of tight tissue for some women.

3. Cording is only in the arm.

Untrue

Almost all cording originates from scar tissue at the breast/chest area. Sometimes cording can be felt on the side of the rib cage.

4. Cording will always respond to arm stretching.

Untrue

Sometimes cording needs to be treated using specialised massage techniques.

5. Cording has gone away if you can reach your arm to beside your ear.

Untrue

Cording may still be present. Less obvious cording can be detected using an alternative testing method. This less obvious cording could be impacting on shoulder and hand strength.

We need to increase informed conversations about cording.

Myths can only be negated with research.
Research into cording has been extremely limited, with the first medical scan of cording only being performed in 2012.

Cancer or Oncology Rehabilitation has been a recent field of study. The main reason for this is the significant improvement in the percentage of people surviving cancers over the last two decades.

Research into this area has been poorly supported and lacks the study group numbers and quality study designs to facilitate rapid change or integration into the field of cancer care.

Why self-assess Cording?

Self- assessment offers a way of having a timely and confident conversation with your breast cancer team member. You will be able to provide information about how cord like tight tissue affects you and more importantly ask about your treatment options.

Cording can cause:

- pain when reaching to do normal daily tasks;
- weakness in the arm and hand;
- shoulder blade and arm movement imbalance;
- increased risk of additional shoulder complaints later on eg tendonitis or frozen shoulder;
- breast pain; and
- a physical barrier to the lymph system and remaining nodes in the armpit.

Cording may just disappear over time, especially thin string-like cords.

Unfortunately, some women do not experience a reduction in cording tightness over time or with usual daily activities and movements. However, the tightness within the tissue can respond to various rehabilitation treatment approaches.

Treatment approaches will not be covered in this e-book, as the focus is on you developing your skills in assessing for tight tissue restricting your movement recovery. See the link to Share Cording Protocols Project for general descriptions of treatment techniques (page 28).

After going through these tests, if you suspect that you have cording, you can confidently seek help. First, consult your breast cancer team. If assessment and treatment services are available at your clinic, then you will be directed to the rehabilitation health professional.

Focus on cording

When it is hard to see (and feel) you could look at it a little differently.

If assessment and treatment services for cording are not available, then this conversation may be the stimulus to access treatment elsewhere or increase the actions by the clinic to provide this service in the future.

General Overview

Cording symptoms vary between women and can negatively impact on quality of life because of pain and limitations in movement or strength. It is important to be able to accurately assess whether cording is restricting your optimal physical recovery.

From extensive clinical study, I have developed a new test for cording and have also adapted the way the tests are performed. These new testing methods can help you find the best way to see if cording may be present. These tests have been used successfully in my clinic for nearly five years to help women easily recognize cording.

This self-assessment guide will take you through two tests:

1. Arm to Ear Test
2. Reach-Out-The-Back Test

The Arm to Ear Test is the first test. It is the easiest test to detect cording when it is very painful and restrictive. If this is the case, it will be physically impossible to advance to the second test, and there is no need for the second test to be performed.

You can use the Arm to Ear Test to measure your recovery after a single treatment or several treatments. As cording improves, the pain and tightness becomes less and you will be able to move your arm closer to your ear.

If you are able to achieve arm to ear movement just as easily as you did prior to surgery, the Arm to Ear Test may not be effective in detecting if cording is present and causing a restriction to your shoulder movement. This is why there is a new Reach-Out-The-Back Test. This test will help determine whether you have achieved your normal movement or whether cording is limiting your optimal physical recovery.

Photos show how cording can not be seen (or felt) in Arm to Ear Test (left) but can be seen and felt in the Reach-Out-The-Back Test (right).

Arm to Ear Test

Reach-Out-The-Back Test

General Overview continued

Both tests will be performed while lying on your side. Side-lying position has been chosen over doing the test in either a seated or standing position. The simple reason for this is that in both sitting and standing, breast tissue can extend across the side rib cage, under your armpit, and may conceal deep tight tissue which can form following breast surgery.

You will be guided to use a simple technique to stretch the soft tissue at the side of the breast and armpit. This will help to find deeper less obvious cording if it is present.

Touching the tight tissue /cording is also possible during this assessment. Your touch at the tight tissue can be with:

- an open, flat hand where your four fingers are feeling for the tight tissue;
- a gentle and soft pinch at the outside edges of the cord between the four fingertips and thumb; and
- a slow and gentle four finger press against the long side of the cord using your fingertips to feel the tight tissue.

There may be some sensitivity or discomfort if you place some stretch on the tight tissue when using either of these techniques. This gentle approach will not cause any injury to this tissue.

Finally, you will go through a process of gathering your self-assessment data and consider possible barriers to rehabilitation, so you can confidently proceed to the next step - which is finding the right person who can help you with an assessment and treatment service.

Photos show how cording can not be seen (or felt) in Arm to Ear Test (left) but can be seen and felt in side-lying position (right).

Arm to Ear Test

Reach-Out-The-Back Test

The first test: Arm to Ear Test

Your starting position:

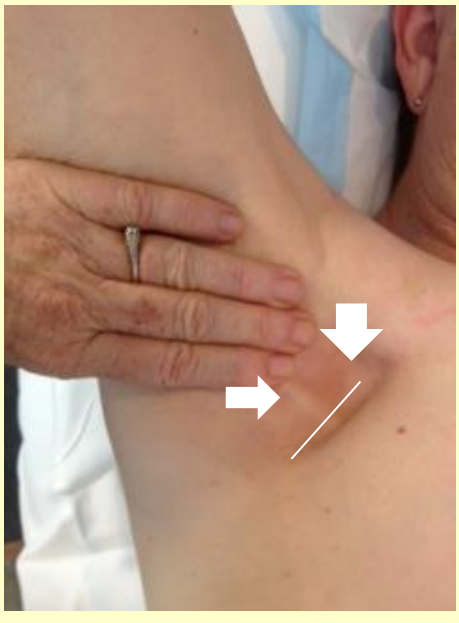
1. Lie on your side with your head supported by a pillow. Have the arm you want to test resting along your (upper) side and leg (‘the side-lying position’).

2. It is important when performing this test that your ear, shoulder and hip are aligned. Imagine a straight line connecting the three points and adjust your head or body to achieve this.

3. This side-lying position allows the breast tissue to fall towards the other breast. Having less breast tissue at the side of your rib cage, allows deeper structures at the side of the breast be more easily seen and felt.

Cording may be easy or very hard to detect.

Go through the steps in the next pages to help you work out if a tight band of tissue has developed during your post-surgical healing.



Cording or AWS is the name used to describe a tight band of tissue extending into the arm, causing pain and a limitation of movement.

It is more than two years after breast surgery for this woman, yet she still has persistent pain in her armpit and breast area and points to the armpit as being the location of pain.

When the arm is stretched in side-lying position and the skin and deeper tissues are stretched, a very wide tight band (larger arrow) of tissue can be seen extending from the breast to the arm with a 1cm cord-like band above this (small arrow). This really did take two people to find this cording.

Based on the description of cording, I believe this is another presentation of cording – yet there is presently no research or discussion about this type of tightness in the literature.

More women need to self test.
More breast cancer team members need to test for cording.
And we need more discussions about physical treatment options.

Arm to Ear Test: Steps and results

Work through these steps to assess if tight tissue can be seen or felt.

Step 1.

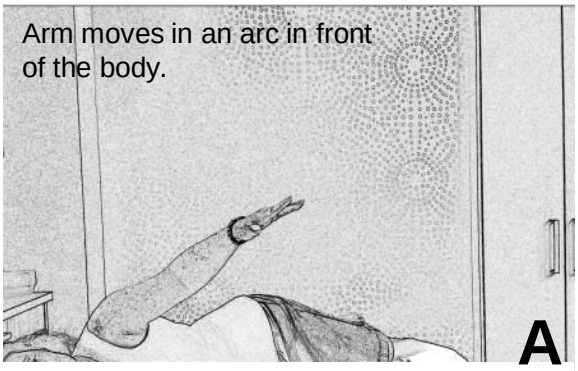
Arm to Ear Test requires you to slowly raise your hand and arm in an arc to bring your upper arm against or towards your ear. You should be aiming to reach as high as you could before surgery.

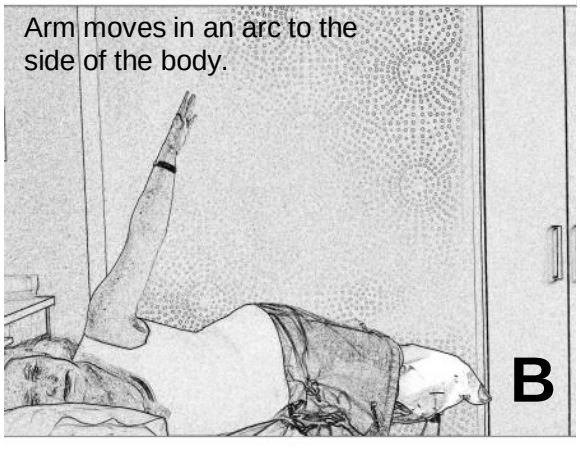
The arc you take your arm through can be:

A. in front of the body or
B. in the direction of the sky/ceiling.

Moving the arm in an arc in front of the body may be the easiest if you have pain.

If pain does not limit you in this direction then try moving in the direction of the sky.





Either way you choose to move your arm, the endpoint you reach is the main objective for this test.

The aim is to find the first point of resistance to your movement when your intention is to touch your ear with your upper arm.

This test does not require you to stretch or reach your arm into any position that is too painful.

Arm to Ear Test continued

If you cannot reach your upper arm to your ear, then work out what is limiting your movement.

With your other hand feel the armpit area and feel if tight tissue is limiting your movement.

If you feel tightness just under the skin, it may feel like thin tight strings there may be one or several.

Alternatively, the tightness may be much wider and thicker. Both of these types of tight tissue just under the skin can be cording.

You could get someone to take a photograph of the tight bands of tissue and compare it to the images seen in this publication.

If the tight tissue is felt and seen in the elbow, you will find that you will not be able to straighten your elbow fully in this test and most likely not be able to reach your arm to your ear.

Make a note of:

- where you feel the pain;
- where the cords can be felt under the skin;
- how thick or thin the cords are;
- if they are thin cords, count the number of cords you see/feel;
- if it is a thick band, describe the thickness; and
- how far away is your upper arm from your ear.

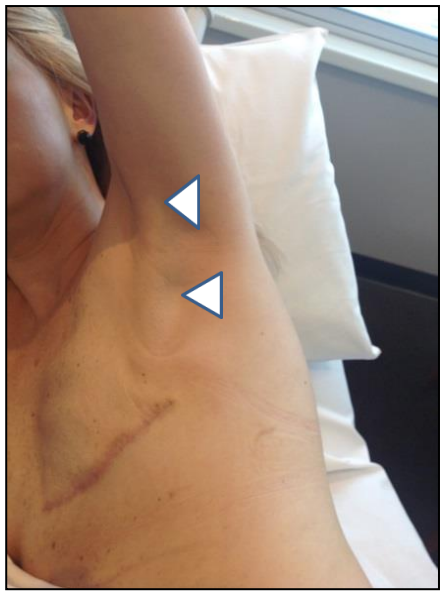
This last point does not need to be measured with a ruler, just identify and remember this position by a descriptive measure.

Examples of measures

My upper arm can get to:

- shoulder level;
- halfway between shoulder and ear;
- near the ear; and
- against the ear.

Step 1: After mastectomy, a tight thick band of tissue extending across into the armpit. It is so tight and painful, that the arm can move to just above shoulder height. Thickness of band is approximately3cm.



Step 1: Four months later, this woman was able to reach half way between shoulder and ear. The thickness of the band is less (2cm).

Arm to Ear Test continued

Step 2

If you **can reach** the upper arm near or against your ear, keep your arm in this position and use the other hand to feel if tight tissue cords or a band of tight tissue can be felt. Again, use a flat hand to gently run over the skin surface or a soft pinch at the thicker band of tight tissue. If tight bands of tissue are detected you could get someone to take a photograph.

Make a note of:

- where you feel the pain;
- where the cords can be felt under the skin;
- how thick or thin the cords are;
- if they are thin cords, count the number of cords you see/feel; and
- if it is a thick band, describe the thickness.

Step 2 : The upper arm can easily reach near or against the ear. No cording can be seen or felt.

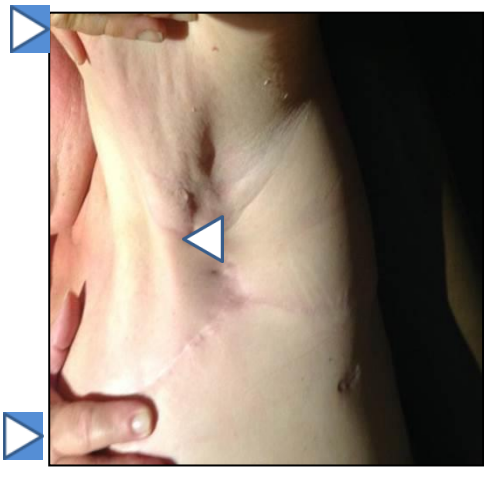
Step 3

If you **can reach** your upper arm against your ear and cording still cannot be seen or felt, use your other hand to gently press into the side breast tissue and gently stretch down in the direction of the belly button. This stretches the skin and soft tissue underneath your hand so you can detect the deeper structures in this area.

In this step, you will not have a spare hand to feel the tight bands of tissue, so either have a photograph taken and/or repeat this step while standing in front of a mirror.

Make a note of:

- where you feel the pain;
- where the cords can be felt under the skin;
- how thick or thin the cords are;
- if they are thin cords, count the number of cords you see/feel; and
- if it is a thick band, describe the thickness.



Step 3 : The use of skin stretch (blue arrow) when the upper arm can easily reach near or against the ear.
Cording can be seen and felt (white arrow)

An example of the Arm to Ear Test

This woman was asked to raise her arm as high as she can, while sitting at her appointment in the surgery.

An inexperienced observer could think:
"*that is reasonable movement considering she has had breast surgery two months ago*".

However, the Arm to Ear Test in side-lying was used at the same appointment and you can see the results below.

Step 1: In side-lying the same limited arm reach can be seen.

Step 2: the upper arm does not reach the ear and this is less movement compared to the other arm.

No cording can be seen or felt but tightness is noticed by the woman at this endpoint.

Step 3: In side-lying, the arm is raised to the ear as far as is comfortably possible.
Gentle hand pressure is used to stretch the skin and soft tissue down towards the belly button (blue arrow).
Cording can be seen and felt by the observer and pain was felt the woman.
Cording is present (at white arrow).

A close up photograph of the cording: The band is about 2.5cm thick, extends from the mastectomy scar to the upper arm.

The hand skin stretch was an important technique to show the cording in this case.

Do you need to progress to the second test?

If you have been unable to detect tight cord like tissue using the Arm to Ear Test then proceed to the Reach-Out-The-Back Test (ROTB Test):

- If you did not feel pain during Step 2 and Step 3 Arm to Ear Test, then proceed to Reach-Out-The-Back Test now;
- If you were not able to complete Step 2 because of pain and reduced movement, there is no need to proceed to the Reach-Out-The-Back Test. Progress to Reach-Out-The-Back Test when you can perform Arm Ear Test Step 2 with less pain; and
- If you do not need to progress to Reach-Out-The-Back Test then go to page 27 to prepare your results.

The second test: Reach-Out-The-Back Test (ROTB Test)

The Reach-Out-The-Back Test should be performed on your non-breast surgery arm first. This will increase awareness of your normal arm movement at three different positions (step 1-3).

Then roll over, check you have the best side-lying position and proceed to test your arm on the side of the breast surgery- going through the same three steps.

Measures are suggested below, so you can best describe how much movement you have, or have not, and if you can feel or see tight bands of tissue. As with the Arm to Ear Test, you could get someone to take a photograph of the tight bands of tissue.

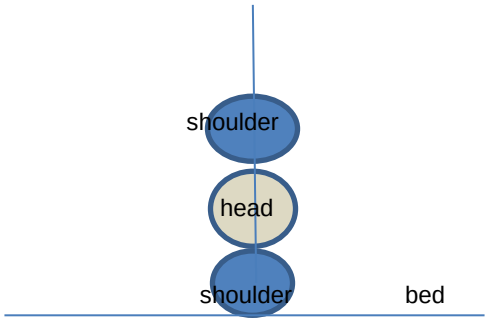
Your starting position:

1. Lie on your side with your head supported by a pillow. Have the arm you want to test resting along your (upper) side and leg (‘the side-lying position’).

2. It is important when performing this test that your ear, shoulder and hip are aligned. Imagine a straight line connecting the three points and adjust your head or body to achieve this.

3. This side-lying position allows the breast tissue to fall towards the other breast. Having less breast tissue at the side of your rib cage, allows deeper structures at the side of the breast be more easily seen and felt.

4. It is important in this test that your side-lying position on the bed is correct. Lie on your side, not leaning or tilting back towards the bed with your upper body. To explain this further, If you draw a line across the bed and then draw a line between both shoulders, you will be at 90 degrees to the bed. Check this position each time you do the Reach-Out-The-Back Test. This will help you to compare your right side and left side arm movement with greater accuracy and confidence.



ROTB TEST

The starting position for your arm.
The clock descriptors used in the following steps will relate to your arm's starting position for this test. If your head is at 12 o'clock and your legs are at 6 o'clock then your arm will be the hour hand.

Step 1:

In side-lying position, raise your hand up in an arc (see sketch **B** page10), until the hand is pointing directly to the ceiling, this will bring you to shoulder height, or 3 o'clock position (9 o'clock on the right arm side). This is your start position for step 1.

Slowly reach your hand back towards the bed behind you. Keep the elbow straight unless tightness and pain at the elbow makes this impossible to achieve.

Reaching out the back is the action you take, and Reach-Out-The- Back position (ROTB position) is the endpoint where you comfortably reach to.

Measure this position by either identifying and remembering how far back you went or take note of how close your hand is to the bed. I do not expect that you use a ruler to measure, but you can have a quick look behind and see how far your hand has gone back.

Examples of measures:

1.

a) I cannot reach back very far at all (or one third)

b) I can reach back a little bit (or half way, two thirds)

c) I can reach back just as much as the other arm did.

Or,

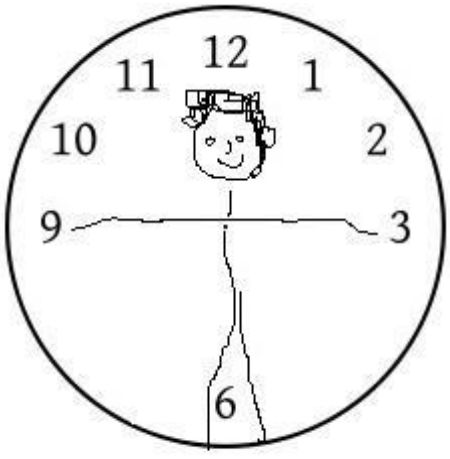
2.

a) my hand touches the bed behind

b) my hand is 2 foot above the bed

c) my hand is 3 foot above the bed.

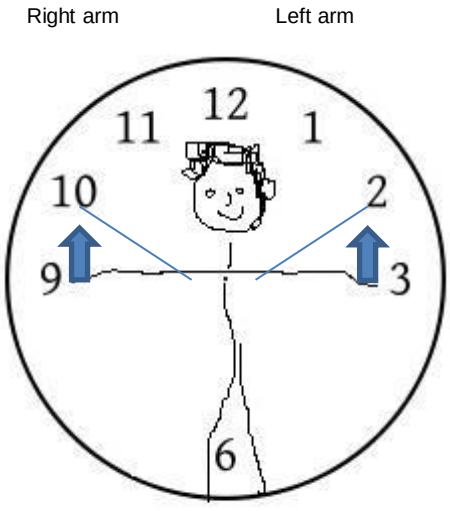
Right arm Left arm



Step1: Left arm is at the Reach-Out-The-Back position.
When I start at the 3 O'clock start position, this is how far I can comfortably stretch back to.
My hand is about 1 foot from the bed.

ROTB TEST

The starting position for your arm.
The clock descriptors used in the following steps will relate to your arm's starting position for this test. If your head is at 12 o'clock and your legs are at 6 o'clock then your arm will be the 2 or 10 hour hand start position.



Step 2:

Bring your arm back to your last starting position and then move your arm to 2 o'clock position (10 o'clock on the right arm side). With the elbow straight, **slowly** let the hand reach back behind you.

In this step, you will try to measure how far back you moved, from your starting point to your Reach-Out-The-Back position.

Example of measuring is:

a) my arm did not reach back at all.
b) my arm reached back a little bit.
c) my arm was able to reach back just as much as the other arm did.

Make a note of:

- where you feel the pain;
- where the cords can be felt under the skin;
- what the cord feels like when you use the other hand to gently press into the side breast and stretch away from the armpit; and
- how far your hand moves back when you reach-out-the-back (ROTB), this endpoint will be called Reach–Out-The-Back position (ROTB position).

An example of the Reach-Out-The-Back position at 10 o'clock.

I started at the 10 O'clock position and then gently stretched back to this position.

I moved about 1.5 foot back from the start position.

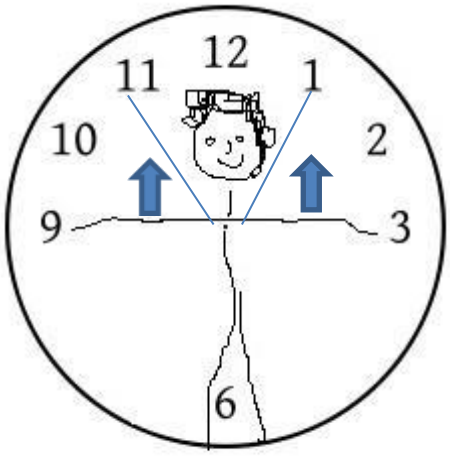
Note: This step will most likely detect any deep, less obvious cording.

ROTB TEST

The starting position for your arm.

The clock descriptors used in the following steps will relate to your arm's starting position for this test. If your head is at 12 o'clock and your legs are at 6 o'clock then your arm will be the 1 or 11 hour hand start position.

Right arm Left arm



Step 3:

Bring your arm back to the last starting position and move to 1 o'clock position (11 o'clock on the right side), keeping the elbow straight, **slowly** let your hand reach back behind you.

Again, try and measure the amount of movement between the start position and the ROTB position.

Example of measuring is:

a) my arm did not reach back very far at all

b) my arm reached back a little bit

c) my arm was able to reach back just as much as the other arm did.

An example of the right arm Reach-Out-The-Back position at 11 O'clock.
I started at the 11 O'clock position and then gently stretched back to this position.
I moved about 10 inches back from the start position.

Make a note of:

- where you feel the pain;
- where the cords can be felt under the skin;
- what the cord feels like when you use the other hand to gently press into the side breast and stretch away from the armpit; and
- how far your hand moves back when you reach-out-the-back (ROTB), this endpoint will be called Reach-Out-The-Back position (ROTB position).

Note: There will be much less reach out the back movement possible at step 3 position compared to Step 1 and Step 2.

These three positions have been selected to allow you to compare your right side ROTB position with your left side ROTB position. Your aim is to do the test on the right side the same as you do the test on the left side, so your comparison will be of similar body tissue (muscle, skin, fascia) at the same place.

Have a go and you will get the idea!

Remember, you do not need to push your arm to a painful position.

An example of Reach–Out-The-Back Test using measures

Step 1 ROTB position

Step 2 ROTB position

Step 3 ROTB position

This would be my measures for this right arm:

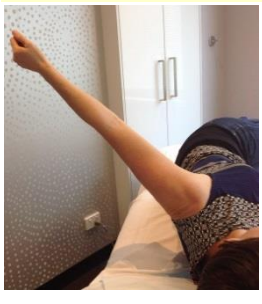
Step 1: My hand is about 1 foot above the bed

Step 2: My arm went back a long way.

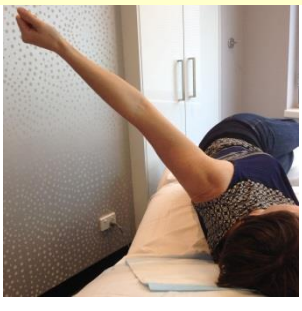
Step 3: My arm went back a long way.

Please note: In this photo series , the woman's head is not correctly positioned in line with the body in side-lying position. We were more concerned about achieving privacy than demonstrating correct side-lying position.
My apologies, it is important to keep the head and body in line during this test.

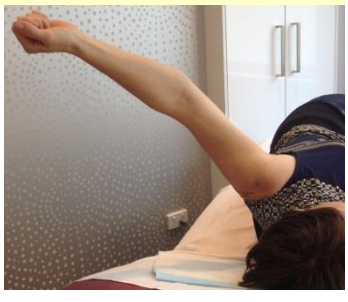
Step 1 ROTB position



Step 2 ROTB position



Step 3 ROTB position



This would be my measures for this left arm:

Step 1: My hand is about 3 foot above the bed, this is about a third of the movement compared to the other side.

Step 2: My arm went back a little bit - about a third of the movement compared to the other side.

Step 3: My arm went back a little bit - about a third of the movement compared to the other side.

NEXT: Meet with your therapist/health professional to establish a diagnosis, rehabilitation goals and plan. Example:

1. Rehabilitation goals: Reduce tightness in left chest and arm so that left arm movement is similar to right arm.
2. Rehabilitation plan: Learn treatments for the left chest area and use these before usual gym/exercise program. Learn correct core stability and shoulder stability patterning.
3. Re- evaluate for improvements in arm movement using the same tests.

Other uses for Arm to Ear Test and Reach-Out-The-Back Test

Arm to Ear Test and Reach-Out-The-Back Test can be used after your treatment sessions to see if you have gained more freedom in your movement and less pain.

By using a measuring strategy as described in each step of both tests, you will be able to tell straight away if your movement is either more or easier within each test.

Progressing from Arm to Ear Test (eg Step1), where you can not get your arm to your ear, to having some movement at Reach-Out-The-Back Test (eg Step 2) is a fabulous example of cording becoming less severe and that you are improving.

Remember that the aim of the test is to see or feel a tight band of cord like tissue is restricting movement in a variety of different positions. In some cases tight cording may **not** be the reason for a difference between the Reach-Out-The-Back Test on the left side to that on the right.

feel or see the difference

compare your measures over time to see if you have improved

In the photos (page 21) there is a clear reduction at the left side Reach-Out-The-Back position in Step 1, 2 and 3. Although cording was seen and felt, it was not tight enough to be a contributing factor to this difference.

In this case, the difference was secondary to radiotherapy changes within the soft tissue of the left chest. It is important to know this as the treatment in this case will be different to the treatment used for cording.

Testing to see if the restrictions in movement are due to scar tissue or tightness in muscles

Both tests can be used to determine if other factors, such as tight muscles, scar tissue, or tightness within the skin, are responsible for reduced movement. Some times the muscles can forget to relax, and some times the lack of stretch in the skin, especially after radiotherapy and breast implant surgery can limit movement.

This testing method requires a few more steps to the tests described here, and offers an answer to the question " is the tightness due to scar tissue or muscle tightness?"

I will cover this in the next e-book as this information helps you work out which tissue is tight and which treatment to use. An example of this is muscle tightness may respond to gentle arm stretch whereas cording and scar tissue may not respond to gentle arm stretch.

When the tight tissue is not cording

Other body tissues can become tight and cause a reduction in movement in the Arm to Ear or Reach-Out-The-Back Tests.

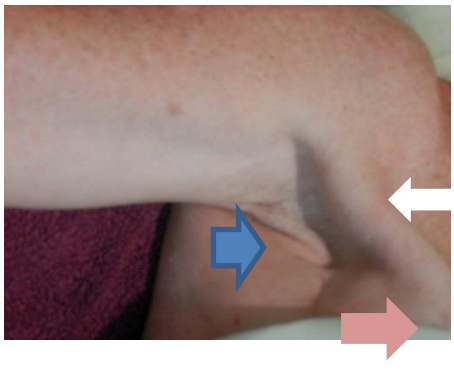
The most common tissue that could feel like a tight band, will be the pectoral muscle. The pectoral muscle extends from the sternum bone (in the centre of the chest) across to the top of the arm bone.

There are many reasons why the pectoral muscle may become tight:

- stress;
- poor rounded shoulder posture;
- radiotherapy;
- mastectomy scar tightness;
- recently inflated expander (for breast implant); and
- partial muscle removal during surgery.

The photos below show pectoral muscle tightness. You can see how the tight pectoral muscle could be mistaken for cording, and you can see that cording can hide behind tight pectoral muscles. This reinforces the need for your assessment to be evaluated by a specialist in the field of breast cancer rehabilitation. Your therapist will help determine which tissue is tight and more importantly what treatment will be most suited.

In the photo (left) **Arm to Ear Test:** The pectoral muscle is at the white arrow and cording is at the blue arrow.
In this case tightness at the pectoral muscle and the skin at the chest (pink arrow) are both restricting movement.



In the photo (left) **Reach-Out-The-Back Test:** The tight band is pectoral muscle (at white arrow) and this is limiting ROTB test.
Cording was present at the blue arrow – but was not the tight band restricting movement.
The skin at the chest (pink arrow) is extremely tight at this test position.

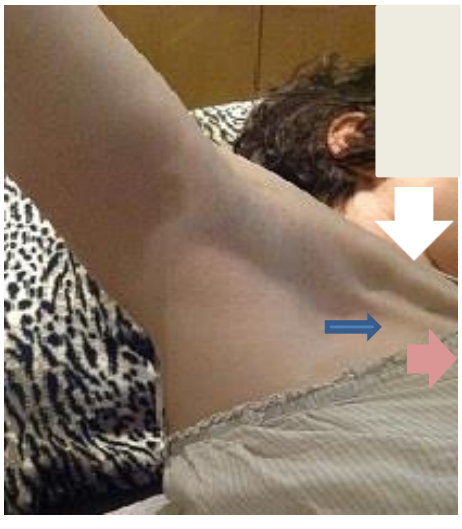
When the tight tissue is not cording continued

In the photo (left) **Arm to Ear Test:** The pectoral muscle tightness is at the white arrow and cording is at the blue arrow.

In this case the tissue at the blue arrow is causing pain in the middle of the upper-arm and movement restriction to the level you see in this photo.

The cording is directly beside the tight pectoral muscle and could easily be missed.

The skin at the chest (pink arrow) is also very tight during this test.



In the photo (left) **Reach-Out-The-Back Test:** The tight band is pectoral muscle (at white arrow).

Cording is present at the blue arrow and is the band restricting movement – pain is felt midway to the elbow at this ROTB position. The skin at the chest is also tight (pink arrow) at this ROTB position.

Pain from tight pectoral muscles is not the same as pain from cording. Pain from cording will be felt on the inside of the upper-arm, midway to the elbow, and possibly extending to the elbow.

The location of pain during the test helps to identify which tissue is causing the pain. This is important information to express to your breast cancer team so include this in your assessment (page 35 section 2).

Skin tightness could be felt during these tests and should be included in your assessment (page 35 section1).

It may be difficult for you to know what the tight tissue is, as such, a photo of the tissue similar to these photos could help when you discuss this with your breast cancer team member.

If you suspect cording, now get help

Step 1: How to present your results confidently.

Once you have gone through your self-assessment steps, write down your results and measures. This step will help you to put your thoughts into a brief and clear statement of your findings. There is a print page at the end of this book (page 36) to help you with this process.

You will have sufficient information to explain your ***suspicion*** of cording if you present the following four pieces of information:

1. **Where is the tightness:**

   "When I reach Arm to Ear or Reach-Out-The-Back, the tightness is… (name the location)".

   Arm, elbow, wrist, trunk, breast.

2. **Where you feel pain:**

   "**I feel pain here" -** Point to the location where you feel the pain and name the test.

   eg. "when I reach Arm to Ear or Reach-Out-The-Back I feel pain…"

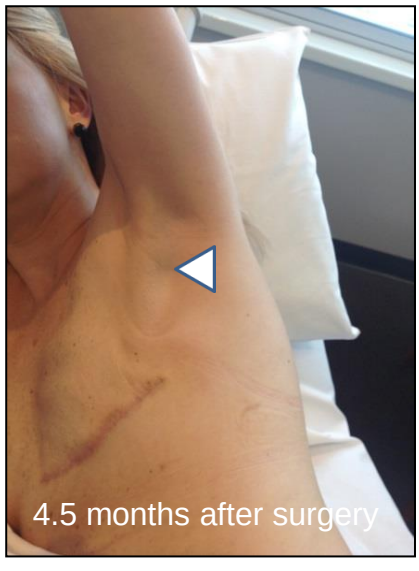
3. **Where tightness limits your ability to reach:**

   "When I compare to my other arm or to what I had before the surgery, I have problems with reaching when I… (refer to the test that best demonstrates your tightness) ".

   You may want to use the suggestions for measures given in the previous section.

4. **What the tight tissue looks or feels like :**

   Your photo will quickly and effectively show the cancer team member what the problem looks like.



Photos on the right show how thick band cording can change over time for this woman.
A physical treatment protocol was undertaken during the first 6 months - the Arm to Ear test demonstrated steady improvement over time. The time frame between the first photo and the last photo is approximately 1.5 years.
Scar tissue can be active for 2 years after surgery and longer after radiotherapy.

Step 2: Go to your breast cancer care team for help.

If you found tight tissue in these tests then cording could be responsible for persistent pain or weakness in your chest, arm or shoulder.

Your next step is to take your photo and the results of your Arm to Ear and Reach-Out-The-Back Test to your breast cancer clinic to seek help. Your aim will be to see if someone at the clinic can help you with a diagnosis and, more importantly, offer treatment options.

If you wish to know more about treatments, timeframes and outcomes for cording before your appointment, then take a few minutes to view Share Cording Protocols Project 2014 on Youtube:

www.youtube.com/playlist?list=PL2FWxNouGN9a-NnDNj0_FEMACpRp5raPx

This reference is a case study project which offers treatment protocols developed and used by some very skilled therapists across the world. The before and after photos in the project offer real examples of the positive changes that can be achieved.

Photos on the right show how thick cording can be missed if Arm to Ear Test is the only test used.

ROTB Test readily shows the tight tissue.

Treatment options can be discussed and ROTB test can be used to evaluate improvement.

Arm to Ear Test: Able to reach ear easily, with no cording seen or felt.

ROTB Test: From 2 O'clock position reach back was not very far because of tight band of tissue.

A close-up photo of the tight band of tissue- cording. The band is about 1.5cm wide.

Will your breast care team know about cording tests?

Your breast care team member will know what cording looks like as it is a common complication after breast cancer surgery. Once you alert the breast care team member to your tight tissue problem, the most common response will be to ask you to raise your arm to your ear so they can see the cording. This test will be sufficient if you have obvious cording.

The tests used by researchers and clinicians over the last decade have relied on arm to ear testing method. Doctors and physical therapists may call this test a shoulder flexion or shoulder abduction test. I have chosen not to use these test names in this self- assessment guide, as I believe that unfamiliar medical words can be a barrier to women being fully engaged in conversations with medical persons about their body.

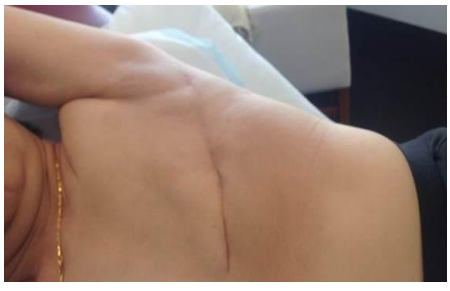
I chose the name Arm to Ear Test because it is easy to say and remember and also describes how to do the test. For the cording self-assessment it really doesn't matter if the arm moves in an arc to the front of the body (flexion) or in an arc out to the side of the body (abduction).

Unless the clinician is very experienced, they may not know about or use the skin stretch technique or Reach-Out-The-Back Test. If your tight tissue was detected using skin stretch technique or Reach-Out-The-Back Test, then you may need to demonstrate these tests or refer the clinician to this testing information.

The Reach-Out-The-Back Test is new to cording assessment and has been designed to better assess and treat a wider range of cording experience. I launched this test in 2014, at the Australian Lymphology Conference with the poster presentation - ***Assessments for Axillary cording and the implications for physical treatment choice and location .***

This photo series to the right shows how the Arm to Ear Test with much deeper pressure allows this woman to detect tight thick band of cording tissue - limiting full recovery. This demonstrates the need to check the tissue (fascia) tightness at deeper layers when pain exists and the cording is difficult to detect with lighter testing methods.

The benefit to this woman is this test confirms her pain experience and directs physical treatment options.



Arm to Ear Test Step 2: Tight cord tissue does not limit movement and can not be seen.

Arm to Ear Test Step 3 with very deep skin and fascia stretch:

With this amount of pressure the arm was not able to reach to beside ear and this was possible on the right side.

A thick band extending from the trunk can be seen. The woman had felt pain near where my hand is.

The tight band can be felt under the skin, where the white arrow is pointed and is about 4 cm wide.

Will your breast cancer team know about cording treatments?

There are very limited numbers of therapists across the world who have worked in the development phase of what physical treatments to use for cording.

There are many reasons for this and I have separated the top three which have been noted for at least two decades:

- medical management during survivorship is primarily concerned with disease recurrence and the late effects of treatment;
- breast cancer medical practitioners believed cording was a normal experience; and
- breast cancer medical practitioners believed cording would go away in time.

Additional barriers to breast cancer rehabilitation:

- relative neglect in the medical survivorship care model for the physical and functional impairments secondary to breast cancer;
- lack of rehabilitation therapists working within breast cancer clinics across the world;
- lack of post-graduate training, specific to the physical rehabilitation needs of breast surgery scar tissue, radiotherapy and chemotherapy;
- focus on lymphoedema as being the main chronic medical issue faced by women after breast cancer;
- lymphoedema therapists, who are most likely to treat women with breast cancer related oedema (swelling) are not standardly trained in cording treatments; and
- lymphoedema treatment is very time demanding. These therapists may have no time for providing rehabilitation services outside of lymphoedema care services.

Because of these medical and educational system barriers, it could be possible that your breast cancer team may not be aware of, or provide, comprehensive treatments for cording.

ROTB Test Step 2: There is less movement back on the right side and the band is about 2 cm thick.

ROTB Test Step 2 with skin stretch: The tight tissue is different to the tissue detected above.

Reducing the barriers to breast cancer rehabilitation

To help reduce some of these barriers, I launched a case study treatment protocol project on Youtube and Linkedin in 2014. Experienced therapists from across the world presented case studies using before and after photos and described their treatments and timeframes. These case studies are not peer reviewed research but have been supplied in good faith by therapists wanting to share information.

The aim of this project was to increase interest and awareness of cording treatments among key health workers in breast cancer care, across the world. During10 months, more than 4,500 breast cancer care health professionals viewed these case studies. This project can be viewed at Youtube: Share Cording Protocols Project 2014 (see the link below).

Breast cancer rehabilitation and indeed cancer rehabilitation are relatively new fields of study and practice. Both fields of practice can be influenced by internet sharing between health professionals and internet information access by women (and men).

If you have found it difficult to get a professional assessment or access to an experienced therapist in your clinic or your town then you have several options:

1. Present concerns about your suspected cording to your clinic and request help. Clinics should respond to this need;

2. Provide internet information resources about cording to your clinic doctor or clinic breast cancer support person eg Share Cording Protocols Project on Youtube.

3. Lobby locally for a breast cancer rehabilitation specialist or

4. Contact Denise Stewart, or any of the therapists who have their contact details on the Share Cording Protocols Project 2014 to see if they can be available for Skype-based help.

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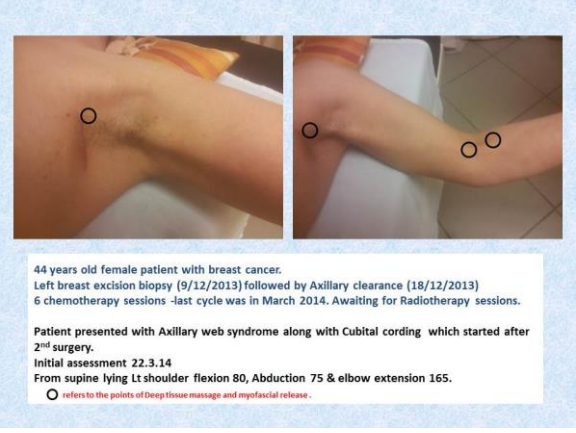

An example of the case study from Egypt on the Share Cording Protocols Project 2014.
http://www.youtube.com/playlist?list=PL2FWxNouGN9a-NnDNj0_FEMACpRp5raPx

Cording: self-assessment guide and current research recommendations

Medical interventions used to treat breast cancer, surgery, radiotherapy and chemotherapy are contributing to physical impairments in the shoulder and arm on the same side as the breast surgery. Research across the world from the last 5 years has identified a high incidence of chronic pain, weakness and other physical symptoms among women after breast cancer. Although the percentage of women who experience pain and impairments varies across study groups, it could be predicted that up to 50% of women experience at least one serious and chronic shoulder/ arm symptom years after their breast cancer surgery.

The seriousness of this negative impact on women lead to a publication of a breast cancer rehabilitation special feature in the *Cancer* journal (April, 2012) by very experienced and concerned physical therapists.

The collection of papers published supported:

- common physical impairments experienced by women secondary to medical treatments for breast cancer;
- identifying barriers to rehabilitation service delivery within the cancer care model;
- the need for screening procedures to identify physical impairments in a timely way ; and
- the need to increase treatment services to help women recover better.

A comprehensive review of 37 research articles on Axillary Web Syndrome (cording) has been published this year (Yueng etal, 2015). The recommendations made from this review are that:

- women should be informed about cording as it is a common experience;
- testing procedures need to be developed to better describe the range of cording experiences;
- routine physical examinations should be performed, to check for cording post surgery; and
- more research to determine effective treatment protocols.

This self-assessment guide offers a comprehensive means of testing your movement and the presence of tightness - which could be cording.

The process described within the *Cording: self-assessment guide* is inline with the current world wide research which is calling for screening and timely service delivery to help women recover better while surviving breast cancer.

Assessment and treatment for less obvious cording, as found with Reach-Out-The-Back Test, may further help reduce the incidence of chronic shoulder impairments experienced by many women.

Acknowledgements

To the women who were happy to share their photos and help in the editing process so we could bring this resource to you and to others around the world. This e-book is richer for their participation.

The recommendations in this guide are made without any specific knowledge of the health system within your country or your town. There will be towns and cities where comprehensive breast cancer rehabilitation services are available and there will be many more towns and cities across the world where these services are currently not available.

My hope is for women across the world with post-breast cancer tissue tightness (in this case cording) receive the specialized rehabilitation services to improve their quality of life.

Positive actions by women in need will help to reduce the barriers to specialist rehabilitation services for women in the future.

Additional Resources:

Axillary Cording : video discussion from Denise Stewart about treatment options, https://youtu.be/2zZwkJOVCN4

Rehabilitation information for women after breast cancer: http://www.breastandshoulder-rehab.com/#!breast-cancer-rehab/cjne

Therapists as expert contacts:

Emad Besher (Physiotherapist Egypt) ptemad@gmail.com

References:

1. W.M Yeung, SM McPhail, SS Kuys: A systematic review of axillary web syndrome (AWS) Journal of Cancer Survivorship published 15.2.2015
2. Sandra C. Hayes, PhD1; Karin Johansson, PT, PhD2; Nicole L. Stout, MPT, CLT-LANA3; Robert Prosnitz, MD, MPH4;Jane M. Armer, RN, PhD5; Sheryl Gabram, MD, MBA6; and Kathryn H. Schmitz, PhD7: Upper-Body Morbidity After Breast Cancer* Incidence and Evidence for Evaluation, Prevention, and Management Within a Prospective Surveillance Model of Care Cancer April 15, 2012.
3. Schmitz K, Speck R, Rye S, Di Sipio T, Hayes S Prevalence of Breast Cancer Treatment Sequalae over 6 years of Followup *Cancer* April 15,2012: 2217-25

Print your quick instructions

Arm to Ear Test

Test the arm on the opposite side to the breast cancer surgery first, then test the surgery side arm.

Check you have the best side-lying position.

Step1 : Raise your arm towards your ear. If you **do not reach** the ear, feel the armpit area (and elbow) to feel if there is tight tissue just under the skin.

Step 2: Raise your arm towards your ear. If you **can reach** your upper arm to your ear, feel the armpit area (and elbow) to feel if there is tight tissue just under the skin.

Step3: With your arm up at your ear, **stretch the skin** and breast tissue down towards your belly button to see if this makes cord like tissue obvious.

Progress to Reach-Out-The-Back Test if you can do Step 2 and 3 without pain from tight tissue.

Reach-Out-The-Back Test

Test the arm on the opposite side to the breast cancer surgery first, then test the surgery side arm.

Check you have the best side-lying position.

Step 1: Start with the arm at 3 O'clock (9 O'clock) position and then gently reach out the back, with a straight elbow. Measure the amount of reach or movement back you have. Aim to touch the bed behind you. Feel for any tight tissue just under the skin.

Step 2: Move your arm to the next start position of 2 O'clock (10 O'clock) and then reach out behind you. Measure the amount of reach or movement back you have. Feel for any tight tissue just under the skin.

Step 3: Move your arm to the next start position of 1 O'clock (11 O'clock) and then reach back behind you. Measure the amount of reach or movement back you have. Feel for any tight tissue just under the skin.

Compare your reach back movement of the right arm with the left arm.

Print your test results

If you need to clarify your thoughts about how to explain this, then use the space below to write down the sentence that best describes what you have found.

Date of breast surgery/s:_____
Date tightness was first noticed:_____
Weeks or months after surgery:_____
Date of radiotherapy (start/ finish):_____
Breast reconstruction tasks (list):
_____
_____

1. Where is the tightness?	
2. I feel the pain here…..	
3. When I reach in this direction (Arm to Ear or Reach-Out-The-Back) my reach is … (use measures)	Arm to Ear Test: Reach-Out-The-Back Test:
4. Is there a photo?	Yes I have a photo or Ask if they want to see the tight tissue.

