

Making a decision about: **Dupuytren's contracture**

What is this document?

This document is called a decision aid. It is designed to help you decide between treatment options. You should go through it and talk to your healthcare professional.

It is for people who have been told they have Dupuytren's disease. Surgery will be an option when one or more of your fingers are bent and you cannot put your hand flat on a table top, and you feel Dupuytren's is starting to impact your daily life.

Pages 1 – 5 should help you make a decision

Pages 6 – 8 have extra information

What is Dupuytren's?

Dupuytren's affects the tissue under the skin of your palm or fingers called the fascia. The fascia becomes thicker and less flexible. Over months or years, it can make your fingers bend towards your palm. This bending is called a contracture. Dupuytren's can sometimes be uncomfortable or painful. There is no cure yet for Dupuytren's disease. Treatment can help to straighten your fingers and may improve the use of your hand, but it does not get rid of the disease.

Needle fasciotomy and open surgery are usually an option if your finger is bent at an angle of over 30° like this

Proximal interphalangeal joint (second finger joint)

Metacarpo-phalangeal joint (first finger joint)



Progression of Dupuytren's disease

The first sign is often a small hard lump in the palm of your hand called a nodule.

Nodules may then thicken into a cord that restricts movement of the fingers.

Your treatment options:

There are several options for treatment of Dupuytren's contracture. Which is best for you will depend on your contracture and personal feelings. Some other options for early disease are described on page 6.

Do nothing







Open surgery fasciectomy



Open surgery dermofasciectomy

2 Treatment options

Do nothing

This means having no treatment. It is always your choice whether to have treatment or not. If your Dupuytren's contracture isn't impacting your daily life you might not want to have treatment. Your contracture may not get any better, but it may not get any worse. You can always decide to have a procedure later but if your finger(s) become very bent, treatment may not work as well.

Needle fasciotomy

Your hand will be numbed (using local anaesthetic) and a needle will be inserted in several places along your palm and finger. This will loosen and then snap the thick tissue which causes your Dupuytren's contracture.

It can only be carried out if your contracture is clearly visible (you can easily see the cord). A healthcare professional will be able to tell you if this applies to you.

Open surgery

Fasciectomy

Your hand will be numbed (using local anaesthetic) or you may be put to sleep (using general anaesthetic). Cuts will be made along your palm and finger and the thick tissue causing the contracture will be removed. This is the most common surgery for Dupuytren's contracture.

Dermofasciectomy

This is similar to a fasciectomy but you will also have a skin graft taken from elsewhere on the body. This is because some of the skin from your palm or finger is removed along with the contracture. This procedure is usually carried out in people under 40, people who have already had a fasciectomy in the past, or people whose skin is involved in their contracture.

When you have treatment for your Dupuytren's contracture it does not cure the disease. That means there is a chance that your Dupuytren's contracture will return after treatment. This is called recurrence. It can return to the same finger and hand or a different place. The risk of recurrence depends on your age, the severity of your disease and the treatment carried out.

Glossary of terms:

Fascia are your connective tissues *Otomy* means to cut *Ectomy* means to remove

3 What's important to you?

Your personal feelings are an important part of making a decision. Think about what matters most to you in this decision. On each question below, consider your answer and put a mark in the yes or no box, then talk the answers through with your healthcare professional.

	Put an ' X ' where i	an ' X ' where it applies to you		
	Yes 	No		
I struggle with daily activities (because of difficulty gripping and clumsiness)				
I think the benefits of surgery are worth having a procedure				
I would like a procedure even though my contracture could come back				
If you've mainly marked no: doing nothing may be a good option.				
If you've mainly marked yes: needle fasciotomy or open surgery be worth considering.	may			

If you have more 'yes' answers or still want to consider a procedure, complete the next three boxes.

	Put an 'X ' where i	Put an 'X' where it applies to you		
	Yes 	No		
A healthcare professional has told me I am suitable for needle fasciotomy				
I don't mind a higher chance of my contracture coming back				
I would prefer a procedure with a shorter recovery time				
If you've mainly marked no: open surgery may be a good option.				
If you've mainly marked yes: needle fasciotomy may be a good option (if you are suitable).				

4 Potential benefits and risks of options



5 Potential risks of the treatments

Needle fasciotomy	Open surgery Fasciectomy	Dermofasciectomy	
How many people have long-term nerve damage (pins and needles or numbness) in their fingers? (Out of every <u>100</u> people)			
2 people have long-term nerve damage after a needle fasciotomy. 98 don't.2 do98 don't	 3 people have long-term nerve damage after a fasciectomy. 97 don't. 3 do 97 don't 	 6 people have long-term nerve damage after a dermofasciectomy. 94 don't. 6 do 94 don't 	
How many people have 'complex regional pain syndrome' (long-term swelling and pain in the fingers)? (Out of every 100 people)			
1 person has complex regional pain syndrome after a needle fasciotomy. 99 don't.1 does99 don't	4 - 10 people have complex regional pain syndrome after a fasciectomy. $90 - 96$ don't. $4 - 10$ people have complex regional pain syndrome after dermofasciectomy. $90 - 96$ don't. $4 - 10$ do $90 - 96$ don't $4 - 10$ do		
How many people have short-term skin damage or wounds that reopen after surgery? (Out of every 100 people)			
20 people have short-term skin damage after a needle fasciotomy. 80 don't.20 do80 don't.80 don't.	 5 people have wounds that reopen after a fasciectomy. 95 don't. 5 do 95 don't 	 10 people have wounds that reopen after a dermofasciectomy. 90 don't. 10 do 90 don't 	
How long does it take people to recover from the procedure?			
It takes less than 2 weeks to recover from a needle fasciotomy.	It takes 4 – 12 weeks to recover from a fasciectomy.	It takes 6 – 12 weeks to recover from a dermofasciectomy.	

Open surgery on the hand is a major operation. Your wounds should heal within a few weeks of surgery, but full recovery time may take many months. You will need physiotherapy during this recovery period.

These procedures do have other risks but we don't have numbers for them, for example:

- risk of infection after the procedure
- risk of long-term joint stiffness after open surgery
- risk that the skin graft in dermofasciectomy won't work.

6 Other treatment options

The options on this page are for early stage Dupuytren's disease (before you have a contracture of 30°).

Other treatment options for early stage Dupuytren's disease

Radiotherapy

There is some evidence that radiotherapy may slow the progression of the Dupuytren's contracture in its early stages. It is rarely offered on the NHS but it is available privately, which means you would have to pay for this treatment. **One study that looked at what happened to 135 people 13 years after radiotherapy:**



Pain relief

Some people develop painful or uncomfortable nodules on their palm or finger. There are some options that can help manage or reduce this pain.

Corticosteroids

Sometimes steroid injections can be used to treat the early stages of Dupuytren's contracture. These injections do not help with the bending of your fingers but they may help ease painful nodules on your palm or fingers.

3 don't

In 97 out of 100 people, nodules soften In and flatten after 3 injections. wi

In 50 out of 100 people, nodules returned within 1 – 3 years.							
50 do						50 d	on't

Physiotherapy

97 do

There is little evidence that physiotherapy will help slow the progression of Dupuytren's contracture. But if you are feeling pain and tension in your hand, exercises may provide some relief.

7 More information

What causes Dupuytren's disease?

The exact cause is unknown. You are more likely to get the disease if:

- you have close relatives with Dupuytren's
- you smoke or you drink a lot of alcohol

you have diabetes or epilepsy

• you are a man.

If you are diagnosed with Dupuytren's disease you may also get disorders affecting tissue elsewhere in the body. These can affect the feet (called Ledderhose disease) or the penis (called Peyroine's disease).

How many people have Dupuytren's disease?

Dupuytren's disease can develop at any age but you are more likely to get it as you get older.





29 in every **100** people aged **75** have Dupuytren's

Where can I go for more information?

NHS: https://www.nhs.uk/conditions/dupuytrens-contracture/

FAQs: https://dupuytrens.org/faq/

Patient Info: https://patient.info/bones-joints-muscles/dupuytrens-contracture-leaflet

British Dupuytren's Society: https://dupuytrens-society.org.uk

Where did we get our numbers from?

Page 4:

- What happens over 7 years from study of 93 people https://doi.org/10.1302/0301-620X.103B4.BJJ-2020-1364.R1
- Improvement in angles after surgery from a study of 113 people https://doi.org/10.1016/j.jhsa.2006.02.021
- Recurrence rates after 5 years for needle fasciotomy and fasciectomy from a study of 93 people https://doi.org/10.1097/PRS.0b013e31823aea95
- Recurrence rates after 5 years for dermofasciectomy from a study of 103
 people https://doi.org/10.1302/0301-620X.82B1.0820090
- Reoperation rates after 10 years from a study of 121,488 people https://doi.org/10.1038/s41598-020-73595-y

Page 5:

 Potential risks from a review of 113 studies (20,020 people) https://doi.org/10.1016/j.hansur.2017.07.002

Page 6:

- Benefits of radiotherapy from a study of 135 people https://doi.org/10.1007/s00066-010-2063-z
- Potential risks of radiotherapy from a review of 6 studies (698 people) https://doi.org/10.1177/1753193417695996
- Benefits of steroids from a study of 63 people https://doi.org/10.1053/jhsu.2000.18493

Page 7:

 Prevalence of Dupuytren's disease from a review of 10 studies https://doi.org/10.1097/01.prs.0000438455.37604

8 Next steps

Once you have worked through this information you can use this space to write any questions you would like to discuss with your healthcare professional. Bring this document to your next appointment.

Contacts

Name of doctor, nurse or specialist

What are their contact details

Contact details of hospital transport (if applicable)

Next steps

What will happen to me next? (treatments / tests?)		
When will these happen?	When will I be reviewed next?	
What decision do I need to make today? Or when do I need to make a decision?		

Questions for your specialist

These can be about any concerns you may have, for example what you hope for from your treatment decision

Produced by:

Winton Centre for Risk and Evidence Communication and NHS England Date last updated: July 2022 Version 1.1 Conflicts of Interest: None declared Funding: NHS England This decision aid was created with input from patients and healthcare professionals.