A Simplified Description of Dupuytren’s Contracture

I’ve written this from a patient's perspective and my understanding of the disease to provide a simplified explanation of the disease and radiation treatment for it.

As a result of a wound or simply due to ongoing wear, the hands and fingers repair themselves.

With some people during that repair process a white substance called Collagen Type III is generated.

The yellow substance can show itself in the hands in small bumps called "nodules" or strands called "cords".

Cords can be created both in the hand and in the fingers, extending up to beyond halfway up the finger.

The yellow substance making up the cords builds up over time, and then the cords start to shrink in length.

It is the shrinking of the yellow substance in both the hands and the fingers that causes the contracture.

As the yellow substance shrinks in the hand, pits can begin to appear.

The normal curved line across the hand below the fingers can start to get interrupted, and in my case this line almost disappeared in my left hand.

The feel of the surface of the hand starts to change from soft to more hardened in the areas affected. Also the Dupuytren’s affected areas on the fingers can change from a soft tomato feel through to a hardened coconut feel.

If the hand were compared to a landscape it starts out as flat and smooth. With Dupuytren’s hills, ridges and valleys start to appear. The result is that when before you could run your finger across your hand and it would be smooth, it is now becoming bumpy as you run your finger across.

For some reason the area of the hands directly below the little (pinky) finger and ring finger get affected first. In turn these two fingers often get affected first. My father has had operations on most of his fingers (not thumbs).

In its worst form untreated can make fingers permanently bent at 90 degrees or worse.
**Decision Factors in choosing Strahlenzentrum Philips E-Beam Radiotherapy in Hamburg**

- “Why seek treatment for Dupuytren’s Contracture in Germany?” you might first ask. The answer is that, officially, doctors in the UK have only been allowed to perform this treatment for Dupuytren’s since 2010, so the experience base is quite different compared to in Germany where this treatment has been available since the 1980s.

- My father had gone through four hand surgery operations, and these seemed to take significant time to heal. The most recent operation for one finger with a very experienced surgeon in 2012 cost 3,000 GBP. The result was from 90 degrees back to flat again. Not all of the fingers have had the same success.

  Given the known risks of hand surgery, if there was any way in which surgery might be avoided, that would be preferable. I looked at the YouTube presentation of the International Dupuytren’s Society. The ‘Treatment Decision Diagram’ I’ve put together (shown later) gives an overview of the different treatment routes available. (Thanks to one of the Administrators of the forum Spanishbuddha for changes made to the first draft of that diagram.)

- Prof. Seegenschmiedt offers extensive experience with the condition, as evidenced by the Miami Symposium of 2010 in which Prof Seegenschmiedt presented his findings, having worked with early stage Dupuytren’s since 1987. It seemed that a number of patients had traveled around the world to be treated by him.

- It would be a simple trip. As the journey from where I live involves a flight of only just over an hour, and as the Strahlenzentrum is close to Hamburg airport. It really helped to read the reports of other people who had done the same trip. Although I didn’t read the forum in a lot of detail it was clear there is a steady flow of people going to Hamburg for treatment.

- Studies in Germany show about an 85% success rate for radiotherapy treatment. Seeing the YouTube presentation of one of the other doctors (a hand surgeon) at the Miami 2010 symposium helped me decide. "No, if possible I don't want my hands cut up". The objective of radiation therapy is to stop the disease progressing further.

- If I had unrelated radiation needs I'd definitely consider going to Hamburg than the UK, because of cost, expertise and the Strahlenzentrum set up itself. The Strahlenzentrum organisation and equipment is very good.
First Consultation with Prof Seegenschmiedt via email

I emailed an enquiry to Prof Seegenschmiedt. His email address was listed on the International Dupuytren’s Society website (prof.seegenschmiedt @ googlemail.com -- remove spaces if emailing). I attached the images below so that Prof Seegenschmiedt could see what my hands looked like.

Prof Seegenschmiedt referred to nodules changing through various states starting off “soft like a tomato” through to “hardened like a coconut”. He said the hands need to be in a state of change from “soft tomato” to “hard coconut” in order for radiation therapy to be effective.

Prof Seegenschmiedt and I emailed back and forth a few times; he encouraged me to visit Hamburg, having established that I had Dupuytren’s and that my hand was at a treatable stage. He quoted 500-600 Euros per site for a series of treatments. Although I had emailed pictures of my worse hand I thought it likely that he would suggest doing the other hand as well, which had not started to lose range of movement. The only finger that has difficulty straightening on its own is my left little (pinky) finger or as Prof Seegenschmiedt refers to it as "D5".

The treatment was likely to come to a maximum of 2,400 Euros for two hands, visiting Hamburg for two separate weeks, spaced 3 months apart. This equated to 1,920 GBP at the current exchange rate. Two centres in the South of England are charging the same price as each other at 3,500 GBP, including consultation and treatment.

Although the final invoice will vary from case to case, the total cost for "week 1" was 991 Euros for consultations over email, consultations at Strahlenzentrum and actual treatment. At the current exchange rate this was 792 GBP, under half the price of the UK centres who have had less than 2 years’ experience since "NICE" (UK National Institute for Health and Clinical Excellence) authorised the treatment in November 2010. Payment was taken during the week with a VISA card.
The blackened area above is of the "coconut" category and less likely to be helped by radiation therapy.

The highlighted black area on the little finger is now hardened and less likely to be helped by radiation therapy.

In time long past this was a nodule
Now is a flat and scarred pit
with stretched / taut fibrous lines
beyond active stage
Radiation will not help this area
The two images above were taken while putting my hand on an HP computer scanner.
First Consultation with Prof Seegenschmiedt at the Strahlenzentrum, Hamburg

The consultations and the treatment are all in one Radiation Therapy dedicated building.

At first Prof Seegenschmiedt was a bit surprised at my little finger -- it was worse than he thought based on our email discussions. My photos that I had sent (and especially the HP scanner image, in which I pressed down my fingers), did not show the fingers side on. He said that due to the bottom third being at the hardened and scarred stage, radiotherapy might not help it. It dawned on me that in retrospect I had left it a bit late for my left hand. Prof Seegenschmiedt checked my feet for Ledderhose and found one small nodule on the right foot but too small to require treatment.

He then examined my hands and it became clear why I had come to Hamburg. His 25 years’ experience allows him to identify in detail where the nodules and cords are in the hands. His "palpation" of the hands can identify even early stage, small soft cords beneath the surface of the skin.
He marked up my hands, to make sure they are neither over treated nor under treated. The photo also serves as a record for future reference.

The circles indicate NODULES, double lines indicate CORDS, the outer line demonstrates the radiotherapy portal outline. (Ref MHS)

For a comparison see Roger Mirka's hands on the external link below. His hands were at an earlier stage, with fewer markings, and were affected by Dupuytren’s on only one hand.

Also Di, from Australia shows diagnosis photos of Ledderhose on the link below.
Individual Finger Table Top Test

In order to determine the maximum extension of each finger, I've used a modification of the whole hand table top test (Hueston) to check on early stage Dupuytren’s.

It allows for taking a photo snapshot of each individual finger with a side on view.

Using the side of a kitchen worktop, I've positioned my forearm and elbow so that it fully touched the worktop, and my palm flat on the surface. I've then taken a photo of each finger attempting to extend it outwards and upwards as far as it can on its own.

For the "deformed" finger no pressure is exerted downwards to hide the reduced range of movement.

The idea here is that the digital camera doesn't lie. It is so easy with a disease of this nature to think it is better than it really is.

"D3" is the middle finger
"D4" is the ring finger

"D5" is the little finger (pinky) - marked in red because with this finger radiation less likely to help.

The finger photo marked in red is a good example of leaving it too late for radiation. However, the remaining fingers and other hand are likely to benefit.
Contracture of the Hands Themselves

Part of the contracture process is the hand beginning to close up.

It is worthwhile checking for contracture in the hand itself by putting a ruler on its edge across from the base of the thumb to the base of the little finger/pinky.

Comparing my two hands:

In my left hand there is quite a gap in which the straight edge of the ruler does not touch the hand at all (base to base length 10.2 CM). This hand was treated too late.

In my right hand the ruler is just able to touch the hand all the way along its straight edge (base to base length 11.0 CM). This hand was treated at the right time.

Dupuytren’s Disease Stages

Radiation therapy for Dupuytren’s is an early stage treatment intended to prevent disease progression. Stage N and Stage N / I are the most suitable stages. The stages are often referred to as "Tubiana". Since Tubiana, the list of stages have been modified to cater for radiation therapy.
## DUPUYTREN'S DISEASE CLASSIFICATIONS

<table>
<thead>
<tr>
<th>STAGE</th>
<th>Flexion Deformity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>STAGE N</td>
<td>No flexion</td>
<td>NODULES AND CORDS, SKIN RETRACTION, ETC WITHOUT FLEXION DEFORMITY,</td>
</tr>
<tr>
<td></td>
<td>deformity</td>
<td>RADIATION TREATMENT VERY SUCCESSFUL</td>
</tr>
<tr>
<td>STAGE N / I</td>
<td>1 - 10°</td>
<td>AS STAGE N PLUS FLEXION DEFORMITY, RADIATION TREATMENT FAIRLY SUCCESSFUL</td>
</tr>
<tr>
<td>STAGE I</td>
<td>11 - 45°</td>
<td>FOR INFORMATION ON TREATMENT OF LATER STAGES SEE:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>INTERNATIONAL DUPUYTREN SOCIETY WEBSITE</td>
</tr>
<tr>
<td>STAGE II</td>
<td>46 - 90°</td>
<td>MENU: “DUPUYTREN’S DISEASE” − “STAGES AND THERAPIES”</td>
</tr>
<tr>
<td>STAGE III</td>
<td>91 - 135°</td>
<td></td>
</tr>
<tr>
<td>STAGE IV</td>
<td>&gt; 135°</td>
<td></td>
</tr>
</tbody>
</table>
Prof Seegenschmiedt's Diagnosis Notes and Summary:

Prof Seegenschmiedt refers to nodules changing through various states starting off “soft like a tomato” through to “hardened like a coconut”. He says the hands need to be in a state of change from “soft tomato” to “hard coconut” in order for radiation therapy to be effective.

Do any fingers have deformity - if so what angle?
How many Nodules?
How many Cords?
What stage category is the hand?: Stage N, Stage N/I, Stage I, Stage II, Stage III, Stage IV

LEFT HAND: Stage I - 7 Nodules / 5 Cords - D5 "Involvement" of angle 30 degrees.
Stage I because the hand had a finger with 30 degrees deformity.

(Neither hand was at the stage in between which is the N/I Stage. This is a combination stage of Nodules, cords and Stage One with a deformity of 10 degrees or less).

RIGHT HAND: Stage N - 6 Nodules / 6 Cords - zero degrees of deformity.
Stage N because it was at nodules and cords without any deformity.
First Radiotherapy Treatment late on Monday afternoon

NOTE THE LARGE AREA TREATED ON BOTH HANDS –
(EXCLUDED WERE: NAILS, TOPS OF FINGERS, THUMB, BASE OF THUMB)

On the first Radiotherapy Treatment the technician took photos of the hand positions.

Shows the beam's eye view of the radiotherapy portal on the hand's surface with the lead shield cut-out placed in the machine's gantry.(Ref MHS)

Each visit to the treatment room took less than 10 minutes.

The left hand is always treated first. For each hand the "red light" is on for 44 seconds.
Positioning the hands prior to radiation treatments

My view was that there is little point in going to Germany to be diagnosed by the world's expert in the field of early stage diagnosis and treatment of Dupuytren’s, and then not take care in the positioning of the hand at the moment just prior to treatment.

The lead shielding cut out as shown in the photo above was 185mm down the longest straight edge. The angle between the two longest sides (after measuring with a protractor) was at an angle of 40 degrees.

Prof Seegenschmidt has a range of different hand lead shields depending on width and angle of specified treatment area. The lead shield was flat and looked to be about 10mm thick.

On a few occasions the radiation technicians seemed to be in a bit too much of a hurry and wanted to get going before checking the hand position.

To counteract this, I was keen to double check the positioning of the hand a few seconds prior to treatment and only start when I was sure the hand was in the right place. We are talking an extra 5-10 seconds maximum to get this right.

A couple of times, with the technician's agreement, I moved my hand towards me to make sure that the whole of the bottom third of the middle finger D3 (PIP to MCP joint) was visible and therefore treated as per the hand markings made by Prof Seegenschmiedt. In some photos I had seen of surgery for Dupuytren’s the cut line ended just above the PIP joint.
I asked for this photo to be taken with my own digital camera on the first radiation treatment appointment, after the technician had taken the positioning photo for the Strahlenzentrum. This only took a few seconds. I went down to Staples (halfway on the walk to the Strahlenzentrum) and had the image of my hand under the lead cut out printed out.

It struck me that the area of cords near the base of the thumb that Prof Seegenschmiedt had marked out and also discussed in the consultation was not included in the treatment area. This was his plan as the markings on the right hand show the treatment line excluding the cords indicated near the thumb.

I discussed this with Prof Seegenschmiedt in the second consultation whose view was that the hand should be neither under treated nor over treated. However, I angled the hand slightly to make sure this area near the bottom of the thumb was included in the treatment.

After positioning of the hand was complete, a "radiation therapy bolus", which looked a bit like a flat and wide waxy bean bag was put over the surface of the hand.
Further photos taken by a local photographer

Further photos were taken back in England with lighting positioned at an angle to the camera in a studio by a local photographer. This enabled the contours of the nodules to be better seen.

Prof Seegenschmiedt made observations about the natural lines of my hands. If you compare in the photos (link below) the natural lines of my hands:

 LEFT HAND: Natural line across hand still continuous and visible
RIGHT HAND: Natural line across hand interrupted

Noting the state of the natural lines provides further clues as to the progression of the Dupuytren’s disease. To see these large detailed pictures of Stage-N and Stage-I click on this link:  Dupuytren’s Early Stage Photos taken in a studio

These photos also show the skin with rowing calluses which are not Dupuytren’s.
Radiation Treatment Schedule

<table>
<thead>
<tr>
<th>Treatment schedule with Prof Seegenschmiedt 11th June 2012</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>First Treatment Week</strong></td>
<td></td>
</tr>
<tr>
<td>Mon</td>
<td>Consultation with Prof Seegenschmiedt approx 11.30am</td>
</tr>
<tr>
<td>Tue</td>
<td></td>
</tr>
<tr>
<td>Wed</td>
<td>Make appointment with reception for Thursday consultation</td>
</tr>
<tr>
<td>Thu</td>
<td>Consultation with Prof Seegenschmiedt approx 10.00am</td>
</tr>
<tr>
<td>Fri</td>
<td></td>
</tr>
<tr>
<td><strong>Second Treatment Week</strong></td>
<td>3Gy</td>
</tr>
<tr>
<td>Mon</td>
<td></td>
</tr>
<tr>
<td>Tue</td>
<td></td>
</tr>
<tr>
<td>Wed</td>
<td></td>
</tr>
<tr>
<td>12 weeks later</td>
<td>Thur</td>
</tr>
<tr>
<td>plus or minus 2</td>
<td>Fri</td>
</tr>
<tr>
<td>2 weeks</td>
<td></td>
</tr>
</tbody>
</table>

Total dosage **30Gy**

First Week - Each day receiving 3Gys of radiation. Total for week 5 days x 3Gys = 15Gys.

Second Week (3 months later) - Each day receiving 3Gys of radiation. Total for week 5 days x 3Gys = 15Gys.

Total dosage = 30 Gys

"Gy" is the symbol for the "gray" which is the unit of measure of the absorption of ionising radiation.

For the second visit 3 months is defined as "12 weeks later plus or minus 2 weeks".
"Seegenschmiedt 1997" Protocol

I was treated above using a protocol published in an 8-year study that was started in 1997.

To see the full image click on this link at the International Dupuytren’s Society Website:
[link]

This is a link to a .pdf file of a lecture on the Dupuytren’s study 1997-2009 comparing different radiation protocols:
[link]

A textbook called "Dupuytren's Disease and Related Hyper-proliferative Disorders: Principles, Research, and Clinical Perspectives" was published in Jan 2012.
On Page 355 the protocol used at the Strahlenzentrum is described:
[link]

**Technical Specification for Radiation Treatment 1**

Quoted from treatment course information letter:

Use of 4 MeV electrons / 5 mm bolus / lead individual absorber adapted to the RT Portal with 60 degree angle and 12 cm length, broad base.
Second Consultation with Prof Seegenschmiedt

Prof Seegenschmiedt reviewed the treatment week and documentation. He then advised on checking and documenting my own hands every 3 months making notes of changes.

Information for left hand and right hand of:

- Number of nodules
- Number of cords
- Symptoms
- Size of nodules
- Length of cords
- Percentage increase or decrease
- Function / Grip, Spreading.

Checking the early stage cords below the surface is probably the hardest item on the list.

After Radiation Treatment Care

Prof S advised on reducing "mechanical stress" and "chemical stress" on the hands after treatment, particularly in the first 2-3 weeks. I therefore didn't row (on the river) for two weeks after each treatment week. Prof S advised to get some gel gloves to protect my hands, so I purchased some from a cycling shop. Prof S also provided advice on skin cream, which is well described in Roger Mirka's page.

In Hamburg an aftercare advice sheet is provided.

State of Hands - 10 Weeks after Treatment

When actually having the treatment I couldn't feel the radiation - apparently there would have been something wrong if I could.

June 26th 2012. It's been over a week since the treatment and no particular effects.

July 15th 2012. Four weeks after treatment. Comparing to the Individual Finger tabletop test (above), at the moment it seems that my right fingers are now more flexible compared to the photo above. On the left hand there is a very marginal improvement in flexibility with the exception of the little finger which is the same as before.

As per the International Dupuytren’s Society website - radiation therapy cannot make a bent finger straight. The purpose is to stop the progression.

Although not part of the "deal" in getting radiation treatment, it seems that for non-deformed fingers, flexibility can sometimes be improved by radiation.
### Dupuytrens Radiation Therapy in Hamburg

**Flexibility Changes comparing 15th June to 24th August 2012 - 10 weeks after end of 1st phase**

<table>
<thead>
<tr>
<th></th>
<th>Degrees</th>
<th>Degrees</th>
<th>Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Left Hand</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle</td>
<td>D3</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Ring</td>
<td>D4</td>
<td>0</td>
<td>21</td>
</tr>
<tr>
<td>Pinky</td>
<td>D5</td>
<td>34</td>
<td>32</td>
</tr>
<tr>
<td><strong>Right Hand</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle</td>
<td>D3</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
<td>Ring</td>
<td>D4</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>Pinky</td>
<td>D5</td>
<td>0</td>
<td>29</td>
</tr>
</tbody>
</table>

Deformed Finger

Large flexibility improvement

From a study of just 2 hands, my conclusion is that the best time for radiotherapy (assuming Dupuytrens is correctly diagnosed) is when one of D3, D4 or D5 can no longer lift off a table surface without assistance from the other hand and also the fingers show no deformity.
D5 flat / just able to lift off surface

zero degrees before
29 degrees after

29 degrees improvement
State of Hands Updates

February 2014.

Over a year on from the treatment, and both of the hands have not changed in individual measured flexibility since the 10 weeks point described above.

The improvement in flexibility of the right hand (Stage N) which was an unexpected bonus has remained.

Unfortunately there is slightly more contracture in the left hand (Stage I) itself now. The base of the thumb and base of the pinky/little finger are now closer to each other than at time of treatment. (My left hand was categorised as Stage I, over 10 degrees deformation, before treatment; i.e., I made the decision to go for treatment in Hamburg too late for this hand.)

30th March 2016.

I've written the section below following email questions I've received from prospective patients: Following an email enquiry - my hands have not changed much over the years since RT in 2012. I still think that RT with Prof S was the right thing to do in my particular case. Each case is different and the global community for the RT treatment for Dupuytren’s is very small.

In Retrospect Has The Treatment Been Worthwhile?

Absolutely -- as far as I'm concerned I've done as much as I can do to prevent my Dupuytren’s from progressing.

Recently I had another look at my father's hands. He has lumps and bumps all over. He also has multiple surgery scars both straight lines and zig zags.

It is my belief based on the published data that if I need surgery or other treatment in the future it will be minimal or even not at all.
Summary and Comparison of Consultation and Treatment Charges for 2 Hands

Total costs incurred for me for Dupuytren’s Radiation Treatment for 2 hands, 2 weeks of visits including consultations and treatments:-

Prof Seegenschmiedt, Stralenzentrum, Hamburg - 1,438 GBP (British Pounds)
(Stralenzentrum breakdown: 991 Euros first visit + 807 Euros second visit = 1,438 GBP)
(Payment was taken by VISA on the Thursday on each week.)

Comparison quotes with two private clinics in the UK were both the same price at 3,500 GBP (British Pounds). In Germany, according to another patient, prices are restricted by German law, which explains why there is a big difference with the UK clinic and consultation costs.

Starting from the UK by the time I added in flights, hotel and parking at Gatwick the total difference in expense narrowed to about 1,000 GBP cheaper than the UK, but I went to Hamburg to get the best treatment available, not just to shave down the costs.

* When comparing costs choosing the Mercure (Leonardo) Hotel, as I did on both trips, is a relatively expensive option compared to the Mein Hotel which is also on the same road as the clinic.

Summary of Service Provided by Prof Seegenschmiedt

Initial direct consultation via email with most responses within 24 hours during the working week.
Estimate of costs for consultation and treatment.
Initial face to face consultation checking hands and feet on the Monday.
Visual hands analysis.
Manual palpation analysis.
Marking hands with areas of Dupuytren’s.
Taking photo of marked hands and hand on scanner for records.
Discussion on history of condition and notes on analysis of hands of which patient receives a copy.
Decisions on which size / type of lead shielding to use.
Treatment by radiation technicians for 5 days.
Second consultation on the Thursday.
Provision of forms for recording future changes.
Provision of doctors letter which the patient has the option to send to his GP.
Provision of invoice detail.
Second week of treatment similar pattern without markings and photos as not required.
Follow up service via email for a period after final treatment.
How Popular Is This Treatment?
With the commentary on the forum and the amount written about the treatment you'd think it was a big industry.

In fact, Prof S, who is considered as the world's expert in this specialty, said in passing (in 2012) that he has about 200 patients each year from around the world for Dupuytren’s treatment. I was somewhat staggered at such a low number.

I got the impression that a fair proportion of patients were women (who often look after their health better). Also the few patients I spoke to were very well informed and had certainly done their research. Some of the information that I learnt from them I've put on this page.

Prof Seegenschmiedt – Patients’ Reports
It's less likely that I would have gone to Hamburg without these reports below:

1) Roger Mirka from Canada has written several very good reports. He covers in detail the Strahllezentrum experience and other topics such as hand care after radiation and week by week progress:

The reports are listed on the Dupuytren’s Contracture experiences page of www.dupuytren-online.info, under Radiotherapy: Roger Mirka's write ups of his treatment

2) This is a great one page summary from the www.dupuytren-online.de website from a patient from the UK: Advice for visiting the Hamburg clinic (1 page word document created June 2010)

3) A patient makes the journey from Australia from www.dupuytren-online.info website: An Australian visit to Hamburg .pdf file March 2011

Links to specific reports from the International Dupuytren’s Society forum are listed to make them easily accessible:

4) Mike Harrel September 2010 from dupuytren-online.info forum. Mike gives a different viewpoint on hotel location. Mike Harrel visit to Hamburg September 2010

Also on this page is a post from "txmike" about his visit with Prof S, along with a photo of the mark-up by Prof S. This provides another example of Prof S making the decision to treat only one hand (Roger Mirka also just had one hand treated).

5) Michael Winzkowski February 2011 from dupuytren-online.info forum. This report made me aware of the risk of being undertreated if I had radiotherapy in the UK. After seeing a consultant
in the UK, it did turn out that I would have been undertreated if I had not gone to Hamburg. 
Michael Winzkowski visit to Hamburg February 2011

6) Gary Ball May 2012 from dupuytren-online.info forum. Gary made the trip from New Zealand and gave an informative and also quite a humorous report. To see his report scroll down below the picture of the globe. 
Gary Ball from New Zealand May 2012

Gary's visit was for Ledderhose, but Prof S found Dupuytren’s on the hands - not enough to treat. The report mentions the use of a "Dupuytren’s scoring system" which determines if treatment will be done by Prof S.

7) Report from Nigel from dupuytren-online.info. Nigel was treated by Prof Seegenschmiedt before he moved to Hamburg 
Nigel Treatment October 2005

8) Tami’s Story

I very much promote the idea of going to Hamburg as soon as possible after diagnosis if within treatment staging range.

Tami's story indicates quite a progression since the initial thought process about Radiation Treatment about 15 months before actual treatment. The “wait and see” expression crops up again in the posts.

In the staging chart above she, like my own case, is in the "Stage I" category, above 10 degrees deformation prior to treatment. Above 10 degrees contracture is declared upfront as resulting in a reduced chance of radiation therapy working.

Tami’s Forum Posts  (Note: this story is of RT treatment in the USA not Hamburg.)

Tami's series of posts are really helpful as a story about how the disease can progress over a relatively short period of time. Also the story provides a real example of treatment not working as expected or hoped. Her posts initially sound encouraging until her post of 22nd February 2014...

9) Blog re Stress of Decision-Making Process

There is no doubt that there is a fair amount of stress involved in making a treatment decision or just leaving it. A really good blog that probably mirrors the fears and also uncertainties I had (and maybe a lot of people have) is at:  Blog on Dupuytren’s Decisions

10) A UK based Dupuytren’s treatment write-up using phrases such as "Beau lines", "a rather primitive process" and "top half of the nail is starting to fall off on a couple" is at: Bobs Diary
Prof Seegenschmiedt – Questions regarding Dupuytren’s Radiation Therapy

There were some questions about the radiation therapy which I put to Prof Seegenschmiedt via email after the first visit to Hamburg:

Does radiation therapy work on nodules better than cords?
Is there a difference between x-ray and e-beam radiation?
What is the best minimum treatment interval?

For Prof Seegenschmiedt’s email answers CLICK ON:
Dupuytren’s Radiation Therapy Questions with Prof Seegenschmiedt

Photos and information have been directly supplied by Prof Seegenschmiedt for use on this webpage.

Prof Seegenschmiedt - Books
This is a list of books Prof Seegenschmiedt authored or co-authored on Amazon.com:


*Radiotherapy for Non-Malignant Disorders (Medical Radiology / Radiation Oncology)* by Michael Heinrich Seegenschmiedt, Hans-Bruno Makoski, Klaus-Rudiger Trott and Luther W. Brady (Dec 10, 2007)

*Interstitial and Intracavitary Thermoradiotherapy (Medical Radiology / Diagnostic Imaging)* by M.H. Seegenschmiedt and Rolf Sauer (Jul 1993)

*Thermoradiotherapy and Thermochemotherapy: Clinical Applications with Contributions by Numerous Experts v. 2 (Medical Radiology, Diagnostic Imaging and Radiation Oncology)* by M. H. Seegenschmiedt, etc., P. Fessenden and C.C. Vernon (Jan 1996)

*Thermoradiotherapy and Thermochemotherapy: Biology, Physiology, and Physics v. 1: Volume 1: Biology, Physiology, and Physics (Medical Radiology, Diagnostic Imaging and Radiation Oncology)* by M. H. Seegenschmiedt, etc., P. Fessenden and C.C. Vernon (Oct 1995)

*Thermoradiotherapy and Thermochemotherapy, Volume 2: Clinical Applications* by M. N. Seegenschmiedt (5 Mar 1996)
Prof Seegenschmiedt presenting in Miami at the International Dupuyren's Symposium in 2010:

Miami Conference 2010 Prof Seegenschmiedt Presentation

Dr. Heinrich Seegenschmiedt "Radiotherapy for Dupuytren & Ledderhose" 2015 Dupuytren Symposium

Published on Oct 28, 2015

Dr. Heinrich Seegenschmiedt presents "Radiotherapy for Early Stage Dupuytren & Ledderhose Disease" at the 2015 International Symposium on Dupuytren Disease in Groningen, The Netherlands.
Other YouTube Videos

Dupuytren Symposium Groningen Conference Video 2015 (See screenshot below): Groningen Conference 2015 Prof Seegenschmiedt Presentation

The YouTube video below is from an organisation in the USA (I have had no personal contact with this USA based organisation but it is quite a good video about the treatment.): USA based clinic sales presentation

Dr. Eaton's List of Radiotherapy Published Documents

Dr Eaton, who I understand has retired from active surgery, has published a good list of original source published documents on radiation therapy on his Dupuytren’s Foundation website:

List of Published Dupuytren’s Radiotherapy Documents

Int’l Dupuytren’s Society

Thanks to Wolfgang Wach and his team, who founded and runs the International Dupuytren’s Society, website and forum. The International Dupuytren’s Society is like the glue which brings patients and doctors together for the various different Dupuytren’s treatments.

Without this central point of information and communication new patients would have to rely only on the knowledge of their local doctor. Local GP's in many cases will not present all of the possible options.

International Dupuytren’s Society, including patient forums: International Dupuytren’s Society
Additional Web Resources

British Dupuytren’s Society which has links with the International Dupuytren’s Society
British Dupuytren’s Society

According to a post on the Dupuytren’s online forum, this "Seegenschmiedt 1997" protocol is being followed at a centre in the UK. This information was provided by Gary Manley who runs the Ledderhose Blogspot information site.
Ledderhose Blogspot Information Site

Compiled Research Data from various studies showing outcome percentages:
Research Data on Dupuytren’s Radiation Therapy

A question I had was, “How long has this method of treatment been around?”
Early Report on Radiation Therapy in the UK in 1955 also in the Lancet
R Finney, British Journal of Radiology 1955

"A personal account of problems encountered with Dupuytren's surgery and an examination of the causes and avoidance of subsequent re-contracture" by R.Ashby
Dupuytren's Recurrence Report

Following written permission from Prof Seegenschmiedt, I uploaded two photos of my hand to the Wikipedia site as on the talk page medical students commented that they were having difficulty in getting agreements to upload photos. I had a couple of emails with the Wikipedia administrators to check that the upload agreement status was ok.
Wikipedia Page for Dupuytren's Contracture
Officially Published Data (Dupuytren’s Symposium "2012")

There is a lot of data quoted on websites of which the source and accuracy are not verified. The most recently published textbook with recent data is:


This book is a compilation of information from the 2010 Symposium, which covered all accepted methods of treatment for different stages of Dupuytren’s; e.g., surgery, Xiapex etc. This text book is a must for any medical organisation wanting to access 2012 published information.

**RADIATION TREATMENT RESULTS** (Page 360):

- Study minimum follow up time - 5 years
- Study mean follow up time - 8.5 years

**Stage N progression (Nodules and cords only)**

The progression of Dupuytren’s is only 3.5% with the current Seegenschmiedt protocol. Data was for 199 hands with a minimum of 5 years, with a mean of 8.5 years. (Control; i.e., hands with no treatment - data shows progression at 34%)

**MEAN FOLLOW UP PERIOD 8 YEARS**

**RIGHT TIME (STAGE N) - RIGHT PROTOCOL**

- PROGRESSION = 3.5%
- SUCCESS RATE = 96.5%

**Stage N/I progression (Nodules, cords and Stage One deformity of up to 10% deformity)**

There is a big reduction in success of radiation therapy at the N/I Stage, with a reported progression of 30%. Data was for 53 hands with a minimum of 5 years, with a mean of 8.5 years. (Control; i.e., hands with no treatment - data shows progression at 67%)

Radiation is used for later stages but with reducing success. The link below is to a .pdf file which shows pages 349-371 from the "2012" book. Page 360 show the summary results of two different radiation protocols (dosages) compared to a control group. Page 362 shows a summary page of radiotherapy studies since 1955.

Dupuytren’s .org Seegenschmiedt pdf file
**Best Time for Radiation Therapy Also Related to Elapsed Time between First Detection and Treatment**

Following a view that the best time for radiotherapy is at the border of Stage N and Stage N / I, Wolfgang Wach, Chairman of the Dupuytren's society commented:

"I would agree with you if the effectiveness of radiotherapy would not rapidly reduce with the time period between first detection and treatment. If you look at the bar graph on: - [Radiation Therapy Data Page](#), you see that if treated within the first 12 months the probability of progression is 2%; if treated after 4 years, the probability for progression is already at 55%. Staging alone doesn't seem to tell the full story."

Also note the newer photos comparing a non-expert Dupuytren’s diagnosis compared to that of Prof S.
Concerns with UK Doctors claiming to be Dupuytren's Radiation Experts

Originally I went for a consultation with one of the doctors in the UK listed on the International Dupuytren's Society website.

After inspecting both my hands and feet, the UK doctor marked up only part of my left hand. I took a photo of the area he marked up. In hindsight what he marked up was the area of the hand which was most easily visible to him (stringy/stretched tissue and large nodules probably caused through rowing).

It gave the appearance that this doctor had just opened up shop without any initial or ongoing training on this specialism. He missed ALL of the Dupuytren's on my right hand. He missed the Ledderhose nodule on my right foot.

When I got to see Prof S in Hamburg he marked up both my hands and treated them both. The area on my left hand which needed to be treated was completely different to that drawn by the UK doctor. Prof S also diagnosed one small area of Ledderhose on my right foot (not needing treatment at that point). This was later confirmed by someone shining a lamp on the bottom of my foot.

If the Hamburg option had not been available it is likely that I'd have had to opt to be treated by one the UK clinics. The UK doctor mentality of being unwilling to learn directly from Prof Seegenschmiedt's experience is rather curious.
Inconsistent Answers on the International Dupuytren's Society Forum

Without doubt, the forum and the website is an excellent place to get initial information and particularly support.

Fears went through my mind about losing the use of my hands and reading other people's stories helped a lot.

It is odd that the same questions seem to keep cropping up and the replies often seem to be different each time round. This means that we could end up choosing a treatment path based on a "passerby's" incorrect opinion. The forum gives the impression that practitioners in different parts of the world are making up their own dosages of radiation (protocols) based on a guess rather than using the published long term findings.

There seems to be a general misinterpretation of what Prof S means by "active" state. The point Prof S is trying to make is that once an area of the hand has reached “coconut hardness,” then radiation therapy will have no effect.

The measurement of the disease using sensations such as crawling, itching, "aliens running around the hand" are narrated on the forum and don't figure anywhere in Prof S's literature or the four consultations I had with him. I am not saying people aren't having these sensations; they just don't feature in the clinical analysis.

Prof S's main areas of analysis are: Patient History, Disease Stage, Visual analysis, Palpation by touching the hands (and also feet).
The Dubious Advice of "Wait and See"

So many times you see the expression "Wait and See" on the forum, often given by non-specialist doctors. It's the exact opposite message to what Prof S is talking about in his YouTube presentation.

With the benefit of hindsight and knowledge I would have had treatment in Hamburg some 6 years before. I am left with one finger permanently kinked and this really would not have been necessary if I had acted sooner.

Although I am aware of the other non-radiation treatments available, I don't like the aspect that some of the treatments are relatively short term fixes requiring multiple visits at intervals quoted as short as one year.

Wolfgang Wach, Chairman of the International Dupuytren’s Society is the walking proof of this treatment. He had radiation therapy on the bad hand 30 years before, but not on the other hand. The treated hand stayed dormant, the other hand now has contracture. *(Source: Symposium YouTube video and forum).*

The "Wait & See" arguments are: It might never contract / contract badly. It might not be the right time yet.

Counter advice of wait and see (after positive diagnosis): Either decide to rule out Radiotherapy altogether or just get on with it!

Some good posts about early treatment and the Betz Diagram

This is a disease which does not follow a straight line or pre-determined path. The data states that results are best when treated as soon as possible after first detection.

**Early Stage Treatment means "VERY EARLY"**

It was the photo of Roger Mirka's hands in his write-up that spurred me into action.

In the photo Roger's hands show no pits or trenches of contracture in the hand itself, yet this is the only example photo that Prof S has put on his website.

When I got to Prof S' office, I felt as though to some extent I'd "missed the bus" with my left hand. I knew when looking at the photo of Roger's hands that I should have looked into going to Hamburg sooner.
12 Mistakes to Avoid regarding Dupuytren’s Radiotherapy Treatment

1) Waiting until it’s too late.

As soon as a finger can no longer fully straighten on its own it has moved from the N (Nodules) Stage to N/I (Nodules/Stage One Deformation) and the chances of radiotherapy working is starting to reduce for that finger.

If there is too much deformation or the Dupuytren’s is beyond active state ie progressed to Coconut hardness, then it is less likely Prof Seegenschmiedt will treat you. In my case one "beyond hope" finger was ok as the rest of the fingers on that hand would benefit.

Putting the edge of a ruler against each finger and hand will show no gap or light if there is no deformity. If a part of the finger cannot make contact with a ruler unaided then the finger is into N/I territory. (See my left finger above where the PIP joint cannot go straight).

2) Choosing the wrong doctor or wrong treatment centre.

Treatment of too small an area of the hand is frequently stated as a reason why treatment failed in the published medical reports.

3) Missing out on the second phase.

I seriously considered not getting the second phase (as an economy measure). I'm glad I did actually go for it in the end, as the results Prof Seegenschmiedt has had in the past are documented as worse with only half the treatment plan.
4) **Having the gap between treatments less than 10 weeks.**

Again Prof Seegenschmiedt found that the results with the shorter interval were not so good as with the 12 weeks plus or minus 2 weeks. Therefore in recent years he seems to have set this minimum interval. He does schedule a longer interval in some cases when a patient cannot return in 3 months.

5) **Mixing doctors and clinics.**

I considered getting the second course of treatment in the UK, rather than Hamburg. If the results were poor who would I go back to? Splitting the responsibility between clinics cannot work too well if there are questions that need to be asked later on.

6) **To expect more than just the halt of the progression of the disease.**

To expect that all the nodules, cords and pits in the hand will totally disappear with radiation therapy is a mistake. For some patients there is an anecdotal extreme cosmetic improvement in the hands, but I’ve yet to see any before and after photos to back this up. I did however as a "bonus" get improved flexibility in my right little finger as shown in the photos. The nodules on my right hand seem flatter and smaller and less visible but are still there. On 17th December I posted a PC computer scanner image of the improvement of the worse left hand after 5 months.

7) **An expectation that bent fingers will become straight.**

Bent fingers will not become straight with radiotherapy. My little finger, as expected, is still bent after the treatment.

8) **Failure to take good photos of your hands.**

It’s important to make accurate records of the disease when first detected, before treatment, and on a quarterly basis.

The first thing Prof Seegenschmiedt will ask is what date/year did you first see the nodules/cords? He will also ask about the progression of the disease since that date.

9) **Confusing Dupuytren’s with "Trigger Finger" or "Carpel Tunnel"**

These are not Dupuytren’s, and these are worth checking out on the internet to clarify the differences.

10) **Failure to watch the Dupuytren’s Symposium 2010 YouTube video.**

The YouTube lecture is information which is straight from the expert himself.

[Miami Conference 2010 Prof Seegenschmiedt Presentation 15](#)
To me seeing Prof Seegenschmiedt give a lecture to a conference on Dupuytren’s is very informative and also gives a lot of confidence in his first-hand knowledge.

11) Failure to take advantage of the email consultation service that Prof Seegenschmiedt offers.

By sending Prof Seegenschmiedt photos of your hands and also your situation he will give you an opinion based on what he can tell from the information you give.

(There are times when he might be away, so if no reply after 48 hours might be worth checking with reception at the Stralenzentrum at email address: info@szha.info).

In February 2014 it was mentioned on the forum that that Prof S had not responded for 3 weeks. This turned out to be because he had been away on business and replied on his return.

12) Assuming the radiation technician will position the hand correctly.

Sometimes the radiation technicians came across as more focused on getting the procedure going and pressing the button than getting the hand position right. I even went to the extent of having Staples (positioned halfway along the walk) print out both the photos of the hand mark ups and also the hand under the lead cut out for reference during the week. I wanted to make sure that the PIP joint of the middle finger was included in the treatment and on a number of occasions moved the hand towards me. In medical diagrams the finger spiral cords can extend to above the PIP joint.
What Might Happen Without Treatment, Later Down the Line?

Dr. Eaton has presented a range of photos of later stage Dupuytren’s (way beyond the stage in which Radiotherapy would be used). These are great photos which show the potential problems which can develop:

Dr Eaton's Patient Photos

Risks of Too Small an Area of the Hand being Treated

Effectively the only areas of my two hands which were not treated in Hamburg were my thumb and the top of my fingers.

I'm confident that this covered not only the obvious areas, but the areas which are not visible. The UK radiation therapy doctor I visited missed the Dupuytren’s on this hand altogether. He only marked up my other hand.

After visiting Prof S I then went to my physiotherapist and showed him an invisible area near the base of my thumb which Prof S had pointed out. It took several attempts for the physio to identify the cord by touch. This degree of skill required would be inappropriate for rolling out on a large basis with the NHS in the UK.

The objective of the radiation therapy is to include in the treatment the soft white stuff which hasn't yet caused the visible wrinkles and bumps. I've not come across a published study where given positive diagnosis of early Dupuytren's, for one group the whole area of both hands are treated as standard. There is a possibility that the "drawing on the hands ceremony" actually undermines and unnecessarily reduces the result of the treatment given.
National Health Service (NHS) in the UK

Typically NHS doctors do not know about radiation treatment for Dupuytren’s, even though one of the pioneering hospitals for this treatment in the 1950’s were British doctors at the St Thomas Hospital, London. The general overview provided in the 1950’s in the medical literature does not differ that much from today in terms of indication of its overall effectiveness.

R Finney, British Journal of Radiology 1955

Trying to get assistance from the NHS, whilst is a noble effort, will not get you treated quickly or by someone with adequate experience to provide analysis on early stage Dupuytren’s.

Quoting the NHS website:

"You should be aware of the uncertainty about its effectiveness and the possible long-term risk that radiation may cause cancerous tumours".

This information is misleading - giving the impression it is a brand new experimental treatment and that there is no long term data.

Professor Seegenschmiedt and other German doctors have been treating with radiation and publishing documents in relation to early stage Dupuytren’s for over 25 years. A number of links to these documents are on this webpage. With these published documents, there is less uncertainty.

If an NHS doctor does have enough expertise to detect early stage Dupuytren’s, the advice will then often be that surgery is the only option. Also the patient will be told to wait until deformation has reached 20-30 degrees - which is the wrong answer!

NICE is a UK government-funded organisation that publishes guidance based on published medical literature. They have provided incorrect information on their website, in stating only one phase of treatment is necessary in most cases. Why publish this statement on the NICE website when it is just plain wrong?

I wrote to NICE about the information on their website. A couple of letters in response from NICE showed a very third-hand and distant knowledge of Dupuytren’s RT treatment. What was rather strange was that in one of the letters it said that NICE does not give guidelines on the specific treatment itself, yet that is what they have done on their webpage.

NICE misrepresented the risks, implying that there is a history of patients having later had cancer as a result of this treatment. The view held by the International Dupuytren’s Society is that there has never been a documented case of cancer following this treatment.

As Prof Seegenschmiedt describes this as a "theoretical risk" and one which must be stated up front, prior to treatment and signing treatment consent.
Update 7th January 2014. Since the above text was published NICE have now changed the wording under safety in relation to cancer being induced to: "a theoretical adverse event". This better represents the risks.

NICE has yet to review its guidance on the requirement for 2 phases of treatment at an interval of 10-14 weeks apart as standard for all patients.

**Note to Web Page Visitors from the NHS**

There have been a number of visitors to this page from the National Health Service. If a budget is at some time put aside for research, training and treatment within the NHS, please note that Prof S is very approachable and I believe has done presentations to UK doctors in the past.

**Why has my Doctor not heard of this Treatment?**

There is an expectation that a GP knows about every treatment for every disease. This has got to be slightly unreasonable given the advances in medicine.

The NHS is unlikely to properly back this treatment in the near future; in turn, University medical books are unlikely to be updated with this treatment as you cannot get Dupuytren’s RT treatment on the NHS in the UK.

Hand surgeons have been interviewed about Dupuytren’s treatment and in most cases do not mention RT. If all patients took the RT treatment at the treatable stages then 85% of the hand surgery revenue might be lost. Quite a financial disincentive for hand surgeons!

There are a few YouTube interviews from 2011 and 2012 where surgeons are asked about all of the treatments and do not mention RT as an option.

Surgery done well does work. My objective has been to reduce the chance of surgery being necessary.

**Beyond Radiation Treatment**

As patients, our mission should be to do our own research relevant to our own particular case, knowing that a mix of different treatments might even be necessary over the long term.

It might be that Radiation Therapy is not for you or that you are at a later stage. The diagram I've put together gives an overview of the different treatment routes available. (Thanks to one of the Administrators of the forum *Spanishbuddha* for changes made to the first draft)
Treatment Routes for Dupuytrens

Strange Lump in Palm → Strange Pit in Palm → Strange Lump on Finger → Self Diagnosis

Diagnosis: GP Doctor and/or Hand Specialist → Early Stage Options → Radiation Doctor Diagnosis

No Dupuytrens → Later Contracture Stage Options → Hand Surgery

Dupuytrens in ACTIVE State? → Radiation Therapy → Disease Continues → Needle Aponeurotomy (NA)

No → Stops Progression → Finger Deformation not too bad → Naturally Stops

Yes → Radiation Therapy → Decision not to get Treated → Very Bad Deformation → Elective Amputation

Hand Surgery → Xafllex

Monitor and document between diagnosis and treatments;
Recommended monitoring interval is 3 months

Alternative later stage treatments might be possible
Possible repeated treatments
The Strahlenzentrum

The Strahlenzentrum is a very popular centre attracting international patients for various radiotherapy needs from Russia, Italy, USA, Canada, Australia, United Kingdom. There is a spirit of friendliness and good will and the patients say "hello" when a new face arrives in the waiting room. The reception staff are very friendly and helpful.

On each visit to the Strahlenzentrum it is important to "check in" at reception otherwise you will never be called.

Waiting times can vary from what seems just a few minutes to quite a long wait. Bringing a good book "in case" softens the wait.

Keep an ear out; your name will be called in the waiting room. This is the cue to walk down the stairs to the treatment areas. Once called there is no hurry because as soon as you have got down the stairs you are either shown a seat to sit on, or in the case of my first visit a cubicle to sit in. The wait from the point of getting down the stairs is about 5 minutes. Some of the other patients are not at all well and they would probably need a fair bit of that 5 minutes to get down to the treatment area.

On the first treatment they take a photo of the hand position under the lead cut out. I'd bought a camera with me and the technician did not mind taking a photo with my camera as well as shown above. Prof S provides a photo of the hands marked up at consultation time but if you want a picture of the hand under the lead cut out bring your own camera.

Once the photos were taken the technician left the room and then pressed the button to start the radiation. The red light on the wall was on for 44 seconds for each hand. You can not feel the radiation either during the treatment or afterwards.

The technicians are getting a continuous flow of Dupuytren’s patients throughout the year and it comes across that they do a lot of hands, so they are very familiar with the set up and the procedure. Having said that there is a note below about double checking the hand position.
yourself, which only takes a few seconds.

The appointment times are set up so that if there are other Dupuytren’s travelers on the same week they’ll meet in the waiting room. In the past apparently there have been enough Dupuytren’s patients for a "group photo". I found it helpful talking face to face with other patients as it gave further insights into the disease.

The Thursday of the treatment week is payment day, so it is worth being prepared. You are taken up the stairs to the credit card machine. They accepted VISA.

Strahlenzentrum Hamburg,
Langenhorner Chaussee 369, 22419 Hamburg

Tel. +49-40-2442458-24
www.szhh.info

**Strahlenzentrum Video**

The first 60 seconds of this 4 minute video gives a good general impression of the Strahlenzentrum reception and building.

[Strahlenzentrum Cyberknife video](#)

Cyberknife is another of Prof Seegenschmiedt's specialties (the Cyberknife robotic equipment is not relevant for the Dupuytren's treatment).
The idea of putting this link in is just to show the building and Prof Seegenschmiedt.

The reception area shown 17 seconds into the video is where I checked in each day.
The consulting room shown 33 seconds into the video is where I had my meetings with Prof Seegenschmiedt.

One of the technicians who treated me on my visits makes an appearance 45 seconds into the video.

Although Prof Seegenschmiedt speaks German in this video, his English is fluent as shown in the Dupuytren’s 2010 Symposium conference video.
Hotels Near to the Strahlenzentrum, Maps, and Arriving from the Airport

The next section discusses the various hotels and their position relative to the Strahlenzentrum. Also the maps give an idea as to where the hotels are relative to the airport and the Strahlenzentrum.

Mercure Hamburg Airport Hotel (after April 1st 2014 "Leonardo Hotel Hamburg Airport")

Hotel Address: Langenhorner Chaussee 183, Hamburg.

A recent visitor has noted that that the name of this hotel will change after 1st April 2014 to: "Leonardo Hotel Hamburg Airport".

The Mercure Hamburg Airport Hotel was suggested by previous travelers due to it being the closest hotel to the Strahlenzentrum. It is an easy walk on the same straight road and on the same side of the road.

The walk from outside the Mercure Hotel to the Strahlenzentrum usually took me 17 minutes.

When I arrived at the Mercure I was allowed to book into the room at 11am, although booking.com says 3pm check in time. I asked the Mercure receptionist to re-confirm my appointment time by ringing the Strahlenzentrum and I think this helped them locate me on their system. My first appointment time for the Monday of the first week was 12:00pm.

On the second week of treatment on the Monday I did the same thing asking reception to ring the Strahlenzentrum to confirm the appointment time which was just as well as the appointment time
was 5:50pm.

Previous advice was to book via booking.com and this worked well.

On the second time around I was given the option of the same room on the floor above reception. This meant an easy walk rather than using the lift during the week. The rooms on the floor above reception are numbered 2xx.

The arrow (on the pavement/sidewalk) in the picture above shows the direction for the Strahlenzentrum which is on the same side of the road as the Mercure Hotel. The yellow sign in the picture is a LIDL store.

I didn't want to spend too much time in Hamburg Centre, I used my laptop in the lounge area and generally stayed in the local area near the hotel. The reception staff members speak good English.

There are two menus for evening meals and you can eat in the restaurant, the bar or on the patio outside if the weather is ok.

In the evening I ate up by the bar where it was quite sociable and the barman Saks from Thailand is friendly and will take your food order from either menu. This is not the cheapest way to eat. The menus had International and local dishes which were hard to resist.

There is a free wireless internet connection in the lounge area near to the reception. You get the code on a printed card from the reception and it changes daily. If you want internet in your room you can connect via a cable for a charge.

Although other reports said there is a pool, it actually closed down a few years back. There is a running machine, a cycling machine and a sauna.
The courtesy bus runs all day; however, it services several hotels and has only a small Mercure sticker on the right (passenger) side of the bus and works on a booking system. After my first visit to and from the Mercure I'd say it is not a courtesy bus service which fills me with confidence as it is trying to service three hotels and even though I had booked to go to the airport they went without me without checking at reception. If you do use this service, book with reception for the set time and then wait outside looking for the bus with the stickers on the side.

The local 292 bus is a bit more of a known quantity.

To book the Mercure courtesy bus from the airport after arriving, go to the airport information on the upper level (departures). There is a free phone at information where the hotel number is stored in the phone. Arriving at the airport I booked this service but never saw the bus, so after a wait took a taxi from the upper level instead.

The "Airport Plaza" sign on the departures level (upper level) is the standard meeting place for courtesy buses.

The taxi cost me 7.70 euros to the Mercure. If you take a taxi on the lower level they might get annoyed as they have to wait a long time in the queue for business at the arrivals level.

I booked the Mercure again for the second trip. The reception and bar staff members are very helpful and friendly.

On the second trip I took the Bus 292 both to the hotel and back to the airport. The bus stop is on the same level as arrivals (lower level), straight out the exit, turn right for a few metres, and the green and yellow "H" sign is right there.

From the airport the journey costs 1.40 Euros one way to the Wischhofen stop. Alternatively if you have already bought a Hamburg card then no charge is payable. If taking the bus from the airport, then ensure the bus says "292 U-OCKSENZOLL" on the front. From the airport it is just 2 stops to get to Wischhofen. After getting off, the Mercure is 3 minutes’ walk further along the road in the direction of travel of the bus.
The Courtyard Marriott is quite an upmarket hotel. Out of interest I had a look at one of their rooms and was surprised it didn't have a bath, only a shower. The swimming pool looks great. The reception staff members speak good English.

To get to the Strahlenzentrum it would take a 25-30 minute walk. Alternatively the 292 bus which runs every 20 minutes during the day will remove most of the walking. At peak times the bus runs every 10 minutes.

Taxi is an option both ways. There are usually taxis waiting for business outside the Strahlenzentrum.

The courtesy bus from the airport seems very regular for the Marriott and the vehicle is well marked. To book from the airport go to the information desk where there is a free phone with the number for the hotel stored in the phone. The place where the courtesy buses pick up from is the "Airport Plaza" sign on the departures level (upper level).
Mein Hotel

Another Strahlenzentrum traveler was staying at the Mein Hotel. She said it was clean, basic, no phone in the room and no evening meals. Wireless internet connection seemed to have problems. She found her way to the Mein hotel via the train from the airport, which involves one change. The reception staff members speak English, but not as well as at the other suggested hotels. I found the reception person a bit unfriendly and unhelpful as did the traveler that was actually staying there.

The price is significantly lower than the Mercure or Courtyard Marriott.

Also the 292 bus will take you from Airport arrivals downstairs to just next to the Marriott Courtyard Hotel.

To get to the Strahlenzentrum it would take a 25-30 minute walk.

Alternatively the 292 bus which runs every 20 minutes during the day will remove most of the walking. At peak times the bus runs every 10 minutes.
Kocks Hotel

The Kocks Hotel is located very close to the Marriot Hotel.

Here is a report from another Dupuytren’s traveler from October 2012...

I stayed at the Kocks Hotel, it is adjacent / next to the Marriott Courtyard, very close to the airport.

I booked on Wednesday before flying on Sunday for 6 nights, other hotels were not available.

It was 59 Euros per night (single person room with one bed) and optional breakfast was 8 euro per day.

Room and breakfast costs were definitely worth it. The location was very convenient, under 10 minutes’ walk to airport and 25 to 30 minutes’ walk to the clinic.

The hotel has free Wi-Fi internet access, I had a notepad device and easily connected to the web. For those who do not have their own Wi-Fi device, the hotel has one desktop PC computer for guests (next to the lobby), and you get free internet access there. The hotel was not fancy, but was very clean, with good service, great breakfast, great location, and great price. I would choose it again.

Comparison of booking.com quoted prices for 1 person staying - 4 nights - 10th Sept 2012

Mercure - Standard 349 GBP, Superior Twin 381 GBP
Marriot - 434 GBP
Mein - 141 GBP

These prices were quoted in June. Apparently hotels can get booked up in September because of holidays and festivals.

Alternatives to Hotels

If you want to add some originality to your trip, there is a way to avoid hotels.

On my second trip I came across Cristl who has posted on the Dupuytren’s online forum.

Cristl does not like hotels, so chose to hire accommodation during both her stays. There seem to be websites in English selling this sort of short stay accommodation in Hamburg; e.g., Google "renting flat in Hamburg holiday"
Walking to the Strahlenzentrum from the Hotels

I drew a map with the small roads walking from the hotel area to the Strahlenzentrum.

The Strahlenzentrum is on the same side of the road (Langenhorner Chaussee) as the hotels listed on this page. On the map is Staples which is halfway. The last road on the left before the Strahlenzentrum is "Buurredder".

Click here for the map: Hamburg Airport Area Hand Drawn Map

Bringing a rain coat and possibly an umbrella to Hamburg is worth considering.

To get into Hamburg Centre from the Strahlenzentrum, walk from the Strahlenzentrum and turn left into the road Foorthkamp and walk for 10-12 minutes. This will get you to Langenhorn Nord underground station.
LangenHorn Markt Area

The Langenhorn Markt Area is about 5 minutes walk from the Mercure Hotel along Kronsteig. From the Mercure Hotel cross over the road (Langenhorner Chausee). Kronsteig will take you up to the Langenhorn Markt area. The picture above shows the train station.

Next to the train station is a fairly large chemist shop.

On the other side of the road (Kronstieg) there is a street with a pub with an English menu, a fruit shop, an ALDI supermarket and a pizza shop.

Commerzbank is one of the nearest banks to the Mercure hotel. The cash machine is inside the building. To use the cash machine put the card in first, then select English.
Standing outside the Commerzbank with Kaufland in front of you, behind your left shoulder is an undercover shopping area where there is a handy cafe and restaurant.

Close to the Commerzbank is Kaufland which is a very large food supermarket, ideal if you want to keep costs down.

The food supermarket is on the upper level.

On the upper level there is also a cafe which sells good fresh sandwiches and also fresh pastries.
BUS 292 - A Regular and Useful Service

Bus 292 timetable LATTENKAMP-OCKSENZOLL

Bus 292 Timetable

The Bus 292 takes Hamburg Card or Euros.

The 292 bus stop has a sign with an "H" coloured yellow and Green.

The bus 292 stops at the airport arrivals, then stops next to the Marriott Courtyard, then close to the Mercure, it then does a loop to LangenHorn-Markt, then heads towards the Strahlenzentrum. For the Strahlenzentrum the stop is "Foorthkamp". You have to press the stop button for the bus to stop. From Foorthkamp the Strahlenzentrum is a couple of minutes walk in the same direction as the bus and then cross the road.

The picture shows the 292 heading towards the Strahlenzentrum from the Marriott Hotel in the OCKSENZOLL direction.

(End of the line is U-OCHSENZOLL)
Foorthkamp............................... Strahlenzentrum
Dreyerpfad
Reestuck
U-Langenhorn Markt
U-Langenhorn Markt
Wischhofen................................. Mercure Hotel
FlughafenstraBe............................. Marriott Hotel / Mein Hotel
S-Hamburg Airport (Flughafen)............ Airport Arrivals Terminal 1 and 2
(End of the line is U-LATTENKAMP)

This bus doesn't necessarily speed things up especially if you just miss a bus, it just saves walking.
The red arrow shows "Langenhorn Markt" which is the closest train station to the Mercure Hotel. It is possible to get from the airport to the Mein Hotel by changing at Ohlsdorf and getting off at Fuhlsbuttel Nord, although taking bus 292 for a single stop to "Flughafenstrasse" is a much simpler option.
I asked at the airport information and at the hotel for a local map and there didn't seem to be one available. I've put together a rough map of the area showing the location of the hotels, where the Strahlzentrum is and also where to get the train into the city.
**Flights from London-Hamburg**

Easyjet had a flight arriving from London Gatwick (South Terminal)-Hamburg (HAM) at 9:50am German time. Hamburg airport is also known as Hamburg-Fuhlsbuttel Airport. I booked this adding on the additional charge for the 20kg luggage allowance.

Going into Hamburg the flight was on time on the Monday morning allowing me to check into the hotel and walk along the road to the Strahlenzentrum.

Returning there was a delay and easyjet flew into a different Gatwick terminal (North Terminal), which required taking the connecting train back to the Gatwick South Terminal. The only giveaway that it was the Gatwick North terminal was the sign just before customs. The flight again flew into the North Terminal on the second trip, this time I was looking for the single sign to show which terminal it was.

On the second trip there was a 50 minute queue to book in for Easyjet and it is worth keeping an ear open for the destinations they are giving priority to in the check-in queue.

The Gatwick Long Stay "Parking Plus" option saves trying to remember where the car is and means the key is safe with them in case of lost baggage on the trip.

The Easyjet return flight itself from London, Gatwick to Hamburg including 20Kg luggage for both trips (4 flights) cost me 115.37 GBP and 86.40 GBP, a total of 201.77 GBP.

(There is a report on the internet that states that the travel costs to London-Hamburg need to be as high as 500 GBP - this is hard to achieve with Easyjet! This report also seems to imply that food costs are significantly different in Hamburg compared to the UK which is not case)
Depending on your feet and the wheels on your suitcase the Marriott and Mein are close enough to walk if necessary. This option is taken by Marriott hotel customers when the shuttle bus has a long wait.
**Cash and EUROS in Hamburg**

Most hotels, restaurants and shops will take credit cards VISA or MasterCard.

However it is worth bringing cash for use on the bus, taxis and other smaller purchases.

As I contingency on a trip to Europe I'd normally take 200-300 Euros in cash. Ideally with mostly smaller notes (20's not 50's). Any EURO notes left over may be converted back again, but not coins.

It will be possible to change to EUROS at any international airport; however, the rate might be cheaper from your local bank or pre-purchase on the internet.

Having the phone details available for your bank is worthwhile as a contingency.

**Mobile Phone**

Unless there is a need to phone back to your home country a lot a mobile shouldn't be necessary for the purposes of getting around in Hamburg.

In any case a pre-pay phone would be available for purchase if necessary from shops in Hamburg Center if required.

Beware of phoning overseas using phones from a hotel room, rates are, in general, very overpriced. Check rates before use!

I did use email a fair bit using the hotel's free internet access in reception.

**Other Information and Sightseeing Ideas**

I bought a DK Eyewitness Hamburg guide book from Amazon. I found the text in this book, particularly the train map, very small. Another Dupuytren’s traveler had a look at it, liked it and said she would buy one for the next trip.

Buying a "HAMBURG card" was mentioned in other reports. I bought a 3 day card on the Tuesday at Langerhorner Markt train station and this covered bus and local trains. Buying a 5-day card might work out better if you are going into Hamburg Center on the Friday as well.

When visiting Hamburg it is best to be prepared for rain. Quite a few days on both treatment weeks were quite wet.

Local sightseeing near to the hotels. A walk around the public paths in the gardens area near to the hotels is quite a good way to spend an hour or so. The gardens area is shown on the hand drawn map (link below). These gardens are separate from houses and similar to the UK idea of allotments, except these gardens have grass and flowers instead of rows of runner beans.
Sightseeing in Hamburg Centre. A good place to start is the gleaming Apple Store at Jungfernstieg. From there you are right in the centre of Hamburg and have a view of the lake. Apple Store Jungfernstieg

Other Sightseeing ideas.
I had a look at the Miniatur Wunderland model train display. Miniatur Wunderland
I was curious as it was voted in Trip Advisor as the No.1 Hamburg attraction. Also a couple I met on the plane had come to Germany specifically to see the exhibition.

I did a trip to Lubeck on the suggestion of Prof S. The train from the Hauptbahnhof (main train station) cost 24.90 Euros return. Once there I did a top of bus tour of the city with a German commentary. There was a booklet in English which you could follow as you go round. Wikipedia Lubeck

I was invited to go to Bergedorf to see a castle by some other friendly Dupuytren’s travellers. This is accessible via the underground train network. Bergedorf Museum and Castle

Some of the other Dupuytren’s traveller reports (links below) provide additional ideas for Hamburg sightseeing.
Has this web page been useful?

Hopefully you have found the information on this page helpful in considering a trip to Hamburg for Dupuytren’s radiotherapy.

If you do go to Hamburg it would be great to receive any comments or updates which you think would be useful.

Other patients have contacted me with questions and updates and I have been able to update the page with this information.

In most cases people do not want to be mentioned by name on the page, if you do please let me know.

If you are a practitioner and feel the wording is wrong on this web page then please do let me know. If I have made a mistake then I'll change it.

If you are considering a visit to Hamburg to see Prof Seegenschmiedt and there are questions you'd like to put to me, my email address is below, taking out the spaces.

Whatever treatment path you take, I wish you the best of outcomes.
Contact Information

The information on this web page is based on visits in June and September 2012. Things change over time - if you see something incorrect please let me know. I can be contacted at cookalastair@btinternet.com.

A large amount of the information on this page has been provided from my own personal experience and also information direct from Prof Seegenschmiedt via email and four consultations in his office in Hamburg.

"Ref MHS" - means this line of wording was provided by Prof Seegenschmiedt.

If you no longer have the link to find your way back to this page at a later date, this page appears on the "External References" list on the bottom of the Dupuytren's Contracture Wikipedia page "Patient experience of Dupuytren’s radiotherapy with photos and notes”

Recent updates

June 2012. Webpage originally created.
February 2014. Update on state of hands added.
22 November 2014. Page moved from pushpullsigns.com domain.

30th March 2016. Update on state of hands added.
11th Oct 2016. List of relevant YouTube videos and links added.

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The document lays out the standard approach and radiation "protocol" for Dupuytren’s radiation treatment as practised by Prof MH Seegenschmiedt.

Please feel free to print to file to create a ".pdf", but please do not modify.

Additional contributors and editors are welcome to contact me.