

# Maintaining mobility in people with thalidomide embryopathy

*Implications of reduced mobility, pain development and therapeutic procedures*

2018

**SCHÖN  
HELFEN**

CONTERGAN  
SPRECHSTUNDE  
HAMBURG

Schön Klinik Stiftung  
für Gesundheit

# **Maintaining mobility in people with thalidomide embryopathy**

Implications of reduced mobility, pain development and therapeutic procedures

## **Editor**

Schön Klinik Stiftung für Gesundheit gemeinnützige GmbH

Managing Director: Anne-Marie Hamm

Seestr. 5 a, 83209 Prien am Chiemsee

Contact person: Rudolf Beyer

Hamburg, 5th November, 2018

© Schön Klinik Stiftung für Gesundheit gemeinnützige GmbH

## **Note**

All information in this work has been compiled and reviewed with the greatest care and diligence. A guarantee for the completeness, accuracy and actuality, however, cannot be given.

We do not accept any liability for any direct or indirect damage which arises from the use of the provided information

Reproduction is authorised, except for commercial purposes, provided the source is acknowledged. Furthermore, it should be noted that the rights to pictures, graphics, text or other information may belong either in whole or in part to third parties.

## Acknowledgements

Painful restriction of movement affects people with thalidomide embryopathy and limb malformations to a particular extent. In September 2017, the Schön Klinik Foundation for Health organised a symposium on the topic of "Maintaining mobility in people with thalidomide embryopathy" in order to achieve something for the preservation and improvement of mobility in conjunction with the patients, doctors and physiotherapists. The present work is a summary of individual reports and discussion papers.

On behalf of Schön Klinik Foundation for Health, I would like to take this opportunity to thank all those who contributed to the Symposium and to this work:

*Margret Aengenheyster*

*Klaus Becker*

*Dehlia Brkitsch*

*Hendrik Bünzen*

*Christina Ding-Greiner*

*Dominique Folie*

*Anette Jonas*

*Sylvia Kunert*

*Jens Lohmann*

*Alexander Niecke*

*Michael Plötz*

*Mathias Prehm*

*Carsten Schmilgeit*

*Jan Schulte-Hillen*

*Dagmar Seeger*

*Jan-Henrich Stork*

*Gernot Stracke*

*Mathias Weber*

*Hilke Weichert*

I would also like to thank the numerous participants for their great interest.

"Last but not least" I would sincerely like to thank Thalidomide Trust, which made simultaneous translation possible through financial contribution.

Rudolf Beyer

## Content

1	Importance of mobility for autonomy and prevention .....	5
2	Importance of staying active for maintaining mobility and prevention .....	7
3	Personal training by sport therapists .....	11
4	Malformations and effects of thalidomide embryopathy.....	16
5	Complaints due to consequential damage .....	19
6	Psychosocial situation of Thalidomide victims.....	21
7	Pain and movement from the perspective of the pain therapist.....	23
8	Pain and movement from the point of view of physiotherapy.....	38
9	Therapy experiences - Conversation with the physiotherapist Jenny Schiller.....	43
10	Anatomical features of the shoulder.....	52
11	Maintaining mobility of the shoulder from an orthopaedic point of view .....	53
12	Maintaining mobility of the spine from an orthopaedic point of view .....	56
13	List of contributors .....	59
14	References .....	60

# 1 Importance of mobility for autonomy and prevention

"Mobility is the most studied and most relevant physical ability affecting quality of life with strong prognostic value for disability and survival. Natural selection has built the "engine" of mobility with great robustness, redundancy, and functional reserve. Efficient patterns of mobility can be acquired during development even by children affected by severe impairments. Analogously, age-associated impairments in mobility related physiological systems are compensated and overt limitations of mobility only occur when the severity can no longer be compensated." (Luigi Ferrucci et al. [1])

Mobility forms the basis for all activities of daily life and thus a prerequisite for independent living. Nutrition, personal hygiene, social contacts, meaningful activities and functions within society are basic human needs. All these activities depend on individual mobility. At the same time, restriction in mobility means restriction in the self-determined way of living.

## ***Specific characteristics due to malformation of extremities***

People with malformations of the extremities are affected to a particular degree, since the personal room for movement is strongly dependent on the form of the disability. Thalidomide victims, who have already developed malformations prenatally, work enormously in the course of their lives to compensate for the functional limitations. However, in last few years, this compensation has been increasingly less successful. The reasons for this are diminishing functions of the musculoskeletal system due to ageing and excessive wear and tear from lifelong overstrain [2].

## ***Specific characteristics due to ageing***

The function of musculoskeletal system is not only weakened by poor joint function. Physiological muscle breakdown (sarcopenia) and reduction of elastic components of the fascia and ligamentous apparatus [3] can additionally impair rehabilitative measures and everyday functions.

## ***Specific characteristics due to limited function of sensory organs***

In addition to malformations of the extremities, people with Thalidomide embryopathy also suffer from disorders of hearing, vision and balance. The limitation in function of sensory organs must particularly concern people with hearing disability and thus incomplete language acquisition, as this represents a massive hindrance to communication and this group is very small. This makes the provision of preventive health care services (Prevention) and access to specialised health services much more difficult.

### ***Importance for preventive health care (Prevention)***

In addition to independent living and social participation, restriction in mobility can also have a negative impact on maintenance of health. Hindrances to exercise or regular physical activity in this age group can have a significant impact on the prevention of hypertension, cardiovascular and metabolic diseases. The need for physiotherapy and massage is very high and is only partially met. Only one third of the demand for acupuncture and alternative methods is covered [2].

### ***Future developments***

Overall, the problems mentioned are expected to worsen in the future as a result of the natural ageing process of Thalidomide victims, who are now around 55 to 60 years old. A particular challenge in developing suitable treatment strategies is the presence of enormous range of various types of deformities within this group. There is no "patent solution" that can apply equally to all patients with Thalidomide embryopathy. This makes it all more important to try out as many different forms of treatment as possible and bring them to the attention of as many affected people as possible. In the end, this is the only way for every Thalidomide victim to decide itself which type of treatment is right for him or her. In order to preserve the acquired skills of everyday activities in the best way possible, all possible forms of therapy should be tested individually.

## **2 Importance of staying active for maintaining mobility and prevention**

*Hendrik Bünzen*

### ***"Sitting is the new smoking" (James Levine)***

*"Our body has evolved over millions of years to not do one thing: sit! Why are we actually so inactive? About 100 years ago, the average walking distance was about 20 kilometres per day. Modern man, on the other hand, manages only 400 - 700 meters in the worst case. The average German sits about 7 hours a day on average and those who do their work at the desk up to 9.6 hours" (Hendrik Bünzen)*

### ***Consequences of a sedentary lifestyle***

A predominantly sedentary lifestyle and physical inactivity are risk factors for variety of diseases, such as cardiovascular diseases and diabetes. However, an inactive, sedentary lifestyle has a particularly adverse effect on the musculoskeletal system, especially in people with malformations.

The problem for musculoskeletal system while sitting arises due to the constant strain that the individual joints and structures are subjected to without any dynamic change. In addition to the continuous and excessive stress caused by the various acting forces, the blood circulation in corresponding structures also deteriorates. At the same time, the muscles, which have a stabilising effect, weaken due to inactivity. Movement, on the other hand, supports joint function as it ensures a better supply of nutrients to the cartilage.

Various studies have shown that the time spent sitting has a noticeable effect on mortality [4–6]. The authors therefore recommended reducing sitting time and increasing physical activity.

The natural ageing process does not only affect the musculoskeletal system. The higher-level control system, namely the brain, also loses its functional reserves over the course of life due to ageing. This leads to limitation of cognitive abilities (information processing, thinking, learning, understanding). Results from various studies have shown that a predominantly sedentary lifestyle accelerates these processes. Mental and physical activity, on the other hand, can improve the functioning of the brain [7].

### ***Benefits of physical activity***

The positive effects of regular physical activity and sports have been thoroughly investigated scientifically and it has been found that physical fitness has significant influence on health. This is not about maximum output or performance, but rather about endurance and appropriate strength training. Strength training is also not contraindicated in patients with cardiovascular diseases

A large number of studies have shown that it is possible to observe immediate effects of training even through simple means [8]. Physical activity can be significantly increased by simple measures (example: 10,000 steps per day). This can contribute towards significant reduction of risk profile for cardiovascular diseases [9].

Structured endurance and strength training can improve the metabolism of sugars (very high blood sugar levels) in type 2 diabetes to a measurable extent (decrease in HbA1c) [10].

In tumour patients, a significant improvement in quality of life could be demonstrated in those who participated in exercise programs during therapy [11].

Training and physical activity can have a beneficial effect on sensation of pain. An evaluation of various studies by the Cochran Institute showed positive effects on pain intensity and improved bodily functions. Although this effect was only slightly pronounced, it was, however, not accompanied by any harmful side effects [12]. This is a huge advantage of training and physical activity over medications.

### ***Can older people also benefit from strength training?***

Many people are convinced that strength training is more suitable for younger people and is not suitable for old age groups. However, various studies have shown that old people can especially benefit from strength training. The following key statements were made in a review [13]:

- Strength training is also effective for older people and does not involve any significant side effects.
- Strength training in older people is subject to a dose-effect relationship. Higher load intensities lead to greater effects than moderate and lower intensities.
- The target parameters of strength training for older people are increase in muscle mass on one hand and neuronal adaptation (inter- and intramuscular coordination) on the other.
- Adding sensorimotor training to strength training in order to optimise posture control is useful for older people with regard to multimodal training programme.
- The benefit of strength training has also been proven in the prevention and rehabilitation of various diseases, including osteoporosis and degenerative joint diseases.



## **Practical recommendations for strength training**

**Table 1: Effects, training doses and organisation of different forms of strength training in older people according to [12].**

<b>Objectives</b>	<b>Training effects</b>	<b>Dosage</b>	<b>Forms of organisation</b>
Increase in muscle strength	Increase in muscle mass	8-12 repetitions per muscle group at 70-85 % of the one-repetition maximum, 3 sets; 2-3 training sessions per week; min. 8-12 weeks	Gym; exercise room; home program; initially under guidance, later independently
	Training of intramuscular coordination	up to 8 repetitions per muscle group at intensities above 80% of the one-repetition maximum; 3-5 sets; 3 training sessions per week; several weeks.	Gym; exercise room; home program; under guidance
	Training of intramuscular coordination	several repetitions; daily training sessions; e.g. high speed of movement	Training on uneven surfaces with and without additional loads; under guidance, then independently
Reduction of sarcopenia	Increase in muscle mass	8-12 repetitions per muscle group at 60-80 % of the one-repetition maximum, 3 sets; 3 training sessions per week; min. 8-12 weeks	Gym; exercise room; home program; initially under guidance, later independently
Adaptation of tendons and bones	Increase of collagen net synthesis; reduction in the decrease of bone density	moderate and high intensities (> 60-80 % of the one-repetition maximum, > body weight); several training sessions per week; weeks to months	Gym; exercise room; under guidance
Prevention of falls and injuries	Optimization of postural control; training of intermuscular coordination	several repetitions; daily training sessions; high speed of movement	Training on uneven surfaces with and without additional loads; under guidance, then independently
	Training of intramuscular coordination	up to 8 repetitions per muscle group at intensities above 80% of the one-repetition maximum; 3-5 sets; 3 training sessions per week; several weeks.	Gym; exercise room; home program; under guidance

***Practical recommendations for people with sedentary lifestyle:***

- Change your sitting and standing positions more often.
- Perform movement in regular phases.
- Make your workplace more dynamic.
- Make a phone call while standing or walking around.
- Spark your creativity while standing or walking around.
- Do exercises that help against muscle tenseness.
- Use the stairs instead of the elevator.
- Use Desktop-Reminder or another reminder function for more movement (e.g. get up and move every 15 minutes).
- Work while standing if you have a standing desk.

Due to the varying degrees of disability in people with thalidomide embryopathy, no general recommendations can be given regarding the right sporting activity. Rather, it is necessary to find out which type of regular physical activity is suitable for each individual. Personal trainers can play a key role here.

### 3 Personal training by sport therapists

*Dominique Folie*

*"My fundamental philosophical assumption is that the river is like a stream of life. Nobody walks safely along the shore. Furthermore, it is clear to me that much of the river is polluted both in the literal and figurative sense. The river may branch out, leading to light currents or dangerous rapids and maelstroms. My work is dedicated to addressing the following question: How do you become a good swimmer when you are in a river, whose nature is determined by historical, socio-cultural and physical environmental factors?" (Aaron Antonovsky [14])*

#### ***The Salutogenesis Model as a conceptual framework for sports therapy***

The concept of Salutogenesis focuses on the interactions between individual risk and protection factors for maintaining health. Health here is not a condition, but a constant process. The human being as an individual is always somewhere between the state of health and illness.

Risk factors or stressors for disease are:

- Chronic stress, e.g. disabilities
- Stressful life events
- Daily irritants

Protection factors or resistance resources:

- Physical resources, for example, a good physical condition
- Material resources, e.g. housing, nutrition
- Attitudinal resources, e.g. belief of self-efficacy, knowledge
- Social resources, e.g. social support from friends and family

The central force for coping with stressors is a continuous and enduring feeling of confidence that...

- everyday events are predictable and understandable (comprehensibility).
- requirements can be fulfilled with existing resources (manageability).
- requirements can be accepted as meaningful challenges (meaningfulness).

According to the model of salutogenesis, as a personal trainer the sports therapist is ideally a temporary supporter who acts according to the patient's wishes, goals and possibilities.

The sports therapist analyses the stressors (disease-causing risk factors) and the goals together with the patient.

The following aspects must be taken into account:

- current physical condition

- restrictions due to disabilities (malformations, barriers, communication)
- physical complaints in everyday life
- physical obstacles in home environment

### ***Comprehensibility***

The sports therapist clarifies the patient's actual state on an anatomical and physiological basis and gives an insight into a possible target state, thus making the situation understandable.

### ***Manageability***

The therapist analyses the patient's current resources (actual state), the means and methods that the patient needs to cope with the stressors and achieve the goals (target state).

Once the training plan has been worked out, the patient and sports therapist implement the contents together, whereby the patient should also train independently. Constant monitoring of success and progress in the training process allows adaptation, if necessary.

### ***Meaningfulness***

The therapist shows the patient the chances and possibilities of training with regard to physical improvement and the preservation of physical functions.

This process helps the patient to understand how the training works and how he himself can contribute ACTIVELY to his state of health. The patient reaps the rewards of his discipline in training and can independently recognise and pursue further goals.

### ***Elements in Personal Training***

#### Organizational

- Health check and analyses
- Training control
- Indoor or outdoor training
- interdisciplinary exchange with therapists and physicians

#### Therapy

- Sports and exercise therapy
- Activity of Daily Living
- Fall prevention
- Sports physiotherapy

- Cardio training
- Medical training therapy (MTT)
- Coordination training / proprioceptive training (deep sensory)
- Fascia training / Kinesiotape / Flossing
- Walking / Nordic Walking / Running
- Mobilisation
- Nutrition advice
- PMR (progressive muscle relaxation) according to Jacobsen

The personal trainer should act as a complementary element of the multi-professional and interdisciplinary team.

### ***Practical recommendation for personal training with Thalidomide victims***

#### 1. Analysis of the current situation

- What restrictions need to be considered (missing limbs, bones, joints)?
- Where is the pain mostly located and how severe is it in the musculoskeletal system (pain scale)?
- Identifying muscular imbalances and degenerative changes in ligaments, tendons, joints, spine)?
- What are the biggest obstacles and restrictions in everyday life?

#### 2. Realistic assessment of the target condition

- Definition of therapy goals.
- Development of a training plan (general muscle building, compensation of muscular imbalances, coordinative aspects).
- Development of compensatory movements for everyday difficulties.

#### 3. Implementation of the training plan

- Common units, patient trains together with therapist.
- Training sessions on your own (Why? For example, shortened muscles require a lot of training to achieve compensation).

#### 4. Success monitoring of training and modification

- Does the training and the intervention work (improvement of the imbalances, relief of the musculoskeletal system, pain scale)?
- If necessary, adjust the training modules.
- Increase the intensity and scope over time.

References: [15] [16,17]

**Figure 1: Training plan for personal training**

Motivation		Last name, First name		Date 19.04.2017			
Dominique Folie Motivation - Rehabilitation & Personal Training <a href="https://www.reha-personaltraining.de/">https://www.reha-personaltraining.de/</a>		Diagnoses: Lumbar spine complaints (low back pain), thalidomide embryopathy					
Training unit 1-8							
Duration	Objective	Exercise		Repetition	s	Break	Note
5 min	Muscular endurance: Abdominal muscles	sit on ball cushions.	a little difficult	20-25	2	1 min.	Stand on your feet. Lean upper body backwards and bend forward again Important: Pressure is felt on abdominal muscles
5 min	Muscular endurance: Lower back	Sit against the wall with the knees bent.	a little difficult	20-25	2	1 min.	Body in sitting position next to the wall, upper body bent forward and raised backward, arms stretched out forwards
5 min	Muscular endurance: lateral	body lifting towards left and right	a little difficult	20-25	2	short, because side is changed	lateral positioning with pillow below the chest, upper body is lifted upwards, make sure that it is lifted only over the side
5 min	Muscular endurance: back of the upper thigh	Bridging	a little difficult	20-25	2	1 min.	Supine position and stand on heels Pelvis is lifted so that a line is drawn between shoulders and knees, then lower the pelvis again
5 min	Muscular endurance: External rotation	Rotate leg outwards with Thera-Band on the left and right leg	a little difficult	20-25	2	short, because side is changed	in lateral position, legs bent at an angle of 90°, heels stay together and upper knee rotated upwards, Thera band kept under tension just above the knees
30 sec/exercise	Classic method of stretching	Stretch directly after performing above-mentioned exercises.	easy	15 sec	2	short	after each strengthening exercise, the respective muscle group can also be stretched directly
3 min	isometric stabilisation	360° exercise	stressful	4 x 15 sec	2	1 min.	Planking, side support from left side, forearm stand, side support from right side--> on-the-fly change of positions, whole body is kept under tension
2 min	Specific stretch M. Piriformis	Half pigeon	easy and exhausting	1 per side	2	short, because side is changed	abdominal position one leg stretched backwards, the other bent under the body --> you can feel the pull in buttocks
3 min	warming up, loosening up	If necessary (loosening, stretching)	easy	1	1	none	The body should be slowly prepared for the end of the strain --> no more heavy strain, cardiovascular system and muscles should "relax"

## **4 Malformations and effects of thalidomide embryopathy**

Contergan damage (thalidomide embryopathy) is a term used to describe a large number of malformations caused prenatally by the intake of Contergan (thalidomide) by the mother during pregnancy. The malformations can in principle affect all organ systems and are extremely different depending on the individual. In addition to bones and joints, nerves, sensory organs, vessels and internal organs can also be affected. The spectrum is enormous and ranges from discrete damage to the thumbs to the complete absence of all 4 extremities.

### ***Primary and consequential damages***

In the case of damage to the skeleton and musculoskeletal system in particular, a distinction is made between so-called primary damage and consequential damage.

Primary damage is defined as all malformations and organ damage that were present at the time of birth.

Health disorders that have only developed over the course of time in Thalidomide victims are considered as consequential damage. The lifelong need to functionally compensate for disabilities caused by malformations with existing limbs has led to excessive wear and tear of muscles, ligaments and joints in the vast majority of patients. The consequences include chronic muscle tension and early-onset arthrosis. As a result, many Thalidomide victims find that the hard-earned strategies and enormous capabilities of functional compensation do not work well.

### ***Damage to the upper limb***

All bones of the hands, arms and shoulders may be completely absent or malformed. The number of fingers can vary and fingers may be fused together. This leads, for example, to shortened arms and a malpositioning of the hands with inward rotation (so-called radial clubhand). The remaining function is strongly dependent on the severity of the disability.

As a result of the shortened arm length or limited gripping function, the back extensors in the shoulder and neck area, as well as all muscles of the shoulder girdle, are overloaded for life. The muscles on the front side, on the other hand, are underloaded and can be shortened. Most Thalidomide victims have painful muscular tension in the neck and shoulder girdle area.



### ***Damage to the lower limb***

Damage to the lower limb by thalidomide occurs less frequently but is much more variable than damage to the upper extremities. They are rarely isolated.

### ***Patient with all four affected limbs***

In addition to the described malformations of the upper extremity, the lower extremity is also affected.

### ***Hip joints***

Malformations of the hip joints (hip dysplasia) are frequent. This leads to early-onset arthrosis with the necessity of an operative joint replacement.

### ***Spine***

Thalidomide victims often suffer from scoliosis and changes in the spine. This leads increasingly to disc diseases and spinal canal stenosis with compression of the nerve roots.

### ***Nerve irritation (nerve compression syndrome)***

The malpositioning of the hands and the anatomical changes can lead to nerve irritation in the wrist area (carpal tunnel syndrome). Pain, tingling sensation and weakness are the consequences. These nerve compression syndromes can also occur in other body regions (elbow, shoulder, lower leg).

### ***Sense of balance***

In some patients, the organ of balance (vestibular organ) in the inner ear is missing. Since its function is compensated from birth (vision, body perception), the absence of such an organ only becomes apparent through special diagnostics (vestibular examination). Frequently, these people report that they have been experiencing increased disequilibrium when walking. A possible explanation for this is that with a decreasing ability of the musculoskeletal system to compensate, the balance disorder becomes apparent.

The result is an increased risk of falling. This means a significantly higher risk of injury for people with short arms.

### ***Hearing loss and deafness***

Hearing loss leads to poorer orientation in the public space and is also a barrier for preventive health care. Deafness, which exists from birth, leads to delayed language acquisition and a lack of understanding of the meaning of words. This also applies to the written word. Overall, hearing loss is a major barrier to participation, prevention and self-care.

***Eye damage***

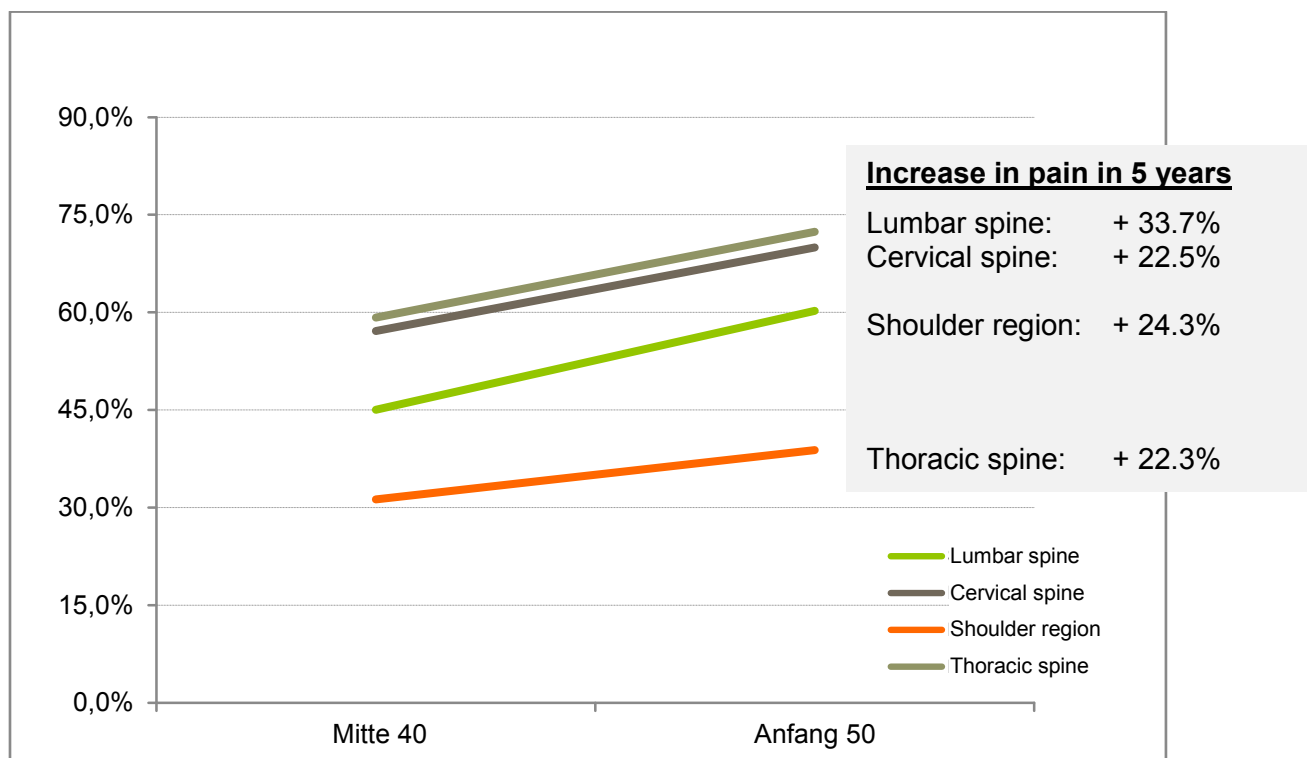
Some of those affected may experience significant loss of vision, blindness and disturbances in three-dimensional vision.

## 5 Complaints due to consequential damage

Many of those affected were able to compensate their disability very well for a long time. However, the physical ability to compensate has been declining significantly for some time and complaints due to consequential damage are becoming more and more important for Thalidomide victims. However, the speed with which complaints have increased in recent years seems to be worrying.

The study by Kruse and Ding-Greiner [2] with 870 participants in 2012 compared, among other things, how many people already suffered from pain in certain body regions 5 years ago, i.e. around 2006-2007, and how many at the time of the investigation between 2011 and 2012. Assuming that the interviewees were born between 1958 and 1963 and that most of them were born in 1962, this part of the survey presents a comparison of about 40-year-olds with about 50-year-olds.

Figure 2: Increase in pain within 5 years according to Kruse and Ding-Greiner.



It is noticeable that within 5 years there was a significant increase in the number of patients who reported pain. (see [2], Page 74, Tab.26)

The second large study on the health situation of Thalidomide victims conducted by Peters and Albus [18] in 2014 involving a total of 202 participants revealed the following points:

- Changes in spine in the form of scoliosis were found in 68.8% of the patients (primary damage).
- In 58.9% of cases, the clinical examination revealed limited mobility of the spinal column. In 36.6% of the patients the cervical spine was affected, while in 22.3% the thoracic spine.
- Limited mobility of the shoulder was found in 62.4%, whereby these restrictions are essentially based on the primary damage.
- 80.7 % reported neck pain, 78.2 % back pain and 64.4 % shoulder pain.

These figures indicate a high degree of painful movement restrictions in the shoulder and neck area and suggest that this problem will increase significantly in the future.

## 6 Psychosocial situation of Thalidomide victims

Alexander Niecke

### ***Mobility and Mind***

In addition to the medical use of the term "mobility" that refers to the movement of the body or individual parts of the body (in contrast to motor function and locomotion), there are also other common uses that present a psychological dimension of the term. Examples for this include "being moved" as an expression of a feeling, "movable" as a paraphrase for mental flexibility and adaptability or "having moved something" as an expression of an outstanding achievement with a lasting effect on others. These ambiguous linguistic uses indicate that physical activity and mental state are closely related and influence each other. For example, extreme forms of movement such as physical stiffness and restlessness are expressions and symptoms of psychological impairments caused by the illness. The creation of a balance is a therapeutic principle in this case and a balanced mobility a basic condition for health.

### ***Biopsychosocial long-term consequences***

Decades after the prenatal trauma of thalidomide use, extensive physical and psychosocial consequences can be proven. This has been convincingly demonstrated in various studies. [2,18]

For example, the subjective quality of life of the victims now aged 55 to 60 is significantly lower than that of the same aged people in the general population and corresponds to values reported for people who are over 80 years old. In addition, Thalidomide victims in Germany are more often unmarried or single due to their disability and have fewer children than the people in the comparable age group. Despite a comparatively high educational status and a high level of occupational skill for many years, the proportion of people who are incapable to work full time is now over 30% [2].

The proportion of Thalidomide victims with psychological disorders is 47.2%, a significant increase in comparison with the age-adjusted general German population (27.1%). The most frequent diagnoses are depression (23%), anxiety disorders (12%), somatoform disorders (14%) and alcohol dependency (6%). However, only about one in six Thalidomide victims (16.6%) suffering from psychological stress has taken advantage of psychotherapeutic counselling within the past twelve months, which points to clear barriers in healthcare [19]. Mental disorders should be politically identified as consequential damage.

Overall, the survivors of the thalidomide disaster have not only grown older, but have also become sicker. On a physical level, the symptoms are now characterised by consequential damage, in particular chronic pain and reduced mobility. In addition, age-associated diseases are becoming increasingly common. The need for assistance and healthcare that had previously arisen was almost completely met by the "lay helper system". Due to the retirement of the parent generation and a relative lack of relationships and descendants, this need is often no longer met. On the psychological level, almost every second person affected

now reports mental health disorders, mostly depression, while at the same time there are treatment barriers in the psychotherapeutic care system.

## 7 Pain and movement from the perspective of the pain therapist

*Jan-Henrich Stork, Rudolf Beyer*

### 1.1 What is pain?

Ancient and essential to human life - the pain processing system is a highly complex warning system of our body, without which we would not be able to survive. From the time of birth, we learn what pain is and how we have to adapt our behaviour in order not to experience it more often than necessary. The whole system is programmed for long-term memory and experience building.

Moreover, humans are social creatures. Because pain usually poses a danger for the body, we would like to learn something about our pain from our fellow human beings. This increases the possibility of receiving help from other members of our social group.

### ***Emergence of pain***

The concept of pain can be understood in a good way by naming the different components (pain components) associated with pain.

#### Pain components

- Sensory:      Damage analysis: Where and how severe is the damage?
- Motor:        Reflex response of the injured body part, self-protection by flight
- Vegetative:   Mobilisation of the body, preparation for flight or fight
- Affective:    Emotionality, signal to social group
- Cognitive:    Hazard analysis, comparison with previous experience, learning

### ***Classification of pain***

Due to different treatment recommendations, it makes sense to differentiate pain in terms of the biological mechanism and its development over time.

**Table 2: Further classification according to mechanism. Nociceptive vs. neuropathic pain**

	<b>Nociceptive pain</b>	<b>Neuropathic pain</b>
Neurobiological mechanism	Pain caused by actual or possible tissue damage (noxious agents) to pain receptors (nociceptors).	Changes in the pain conduction system due to damage to the central or peripheral nervous system.
Examples	Cuts, bone fracture, inflammation, burns	Nerve compression syndromes Postzosteric neuralgia, phantom pain
Biological function	Warning function for the organism	
	Reflex reactions such as withdrawal reflex, muscular defence	
Pain character	stabbing, dull, pressing, boring, colicky	burning, stabbing, sharp
Response to drugs	Good response to opioids and non-opioids	Hard to treat, hardly responsive to opioid. Better anticonvulsants and antidepressants

**Table 3: Further classification according to development over time. Acute vs. chronic pain**

	<b>Acute pain</b>	<b>Chronic pain</b>
Characteristics	Signal and warning function Protection against injury, life-sustaining function Promotes wound healing (Immobilisation)	Loss of biological warning function. No protective or healing function. Pain persists beyond the expected healing time.
Examples	injury, surgery, ischaemia, toothache	Chron. spinal disorders Tumour pain, headache, CRPS, multiple sclerosis, postzosteric neuralgia
Psychological effects	Simple mental processing. Generally good acceptance by fellow human beings	Psychological and social withdrawal. Low acceptance by fellow human beings

### ***Neurobiological pain processing***

For a long time, it was assumed that pain processing works similar to an electric cable. This idea dates back to the scientific treatise "De homine" (treatise on humans) by the French philosopher and scientist René Descartes from the 17th century and lasted until the last century. Since about the 1960s, however, more and more new theories on pain have been developed and researched.



An important function of the pain-processing nervous system is to separate the unimportant from the important. Millions of nerve cells are responsible for this function, each of which ensures the absorption, transmission and processing of pain stimuli. Essential elements here include signal amplification and noise suppression (such as a HiFi stereo amplifier). Our whole body is interspersed with nerve cells, which constantly record information on all stimuli with their sensors (biological: receptors). Pressure on the tissue, temperature, chemical stimuli in the muscles, the position of the joints and body position are constantly measured. Thousands of stimulus information are recorded every second.

In order to avoid a stimulus flooding and thus a system failure, these stimuli are filtered and processed without anyone noticing. A large part of this happens independently in the spinal cord.

In the end, only the important information is passed on. In order to always be able to act, we also have a descending pain control in our central nervous system. This makes it possible to reduce pain sensations and thus keep the pain processing system functional.

Our pain-processing nervous system is capable of astonishing adaptations, which may, however, prove to be disadvantageous in the case of chronic pain. The network of nerve cells can dynamically change important paths of information. This is called neuroplasticity. Some authors also term the result of these adaptations as pain memory. Research in recent decades has identified two mechanisms that play an important role in this process.

### ***Pain sensitisation***

Persistent pain stimuli can lead to a higher sensitivity of the nerve endings. Due to continuous "firing" by a constant stimulus, the nerve cells begin to increase their sensitivity. In addition, the networks of the pain-processing system begin to change their filtering function. The whole system is sensitised, i.e. they become more sensitive. This means that even relatively small pain stimuli can trigger a comparatively large sensation of pain. This generally leads to a relieving posture of the body.

### ***Neurobiological pain chronification***

Long-lasting pain stimuli can lead to new pathways in the pain processing system. The neurobiological properties of the nerve cells are permanently altered and new network connections are formed. Thus, the symptom of pain can become an independent, chronic disorder.

## **1.2 Neuropathic pain - pain development in the nervous system**

If the function of nerves is disrupted, they can be the cause of pain. This is called neuropathic pain and can be caused by damage due to pressure on the nerve or injury to nerves. This pain is then projected into the regions that these nerves normally supply, regardless of the location of the actual damage. Typical symptoms are burning sensation, sharp pain and accompanying symptoms such as tingling sensation, formication or

numbness. Common causes of nerve disorders are: Nerve compression syndrome (carpal tunnel syndrome), diabetes, harmful alcohol consumption and vitamin B deficiency.

### **1.3 Pain in the musculoskeletal system**

The musculoskeletal system consisting of joints, muscles, tendons, ligaments and fasciae is particularly well equipped with pain receptors. Many of these specialised nerve cells are sensors that react to various stimuli (polymodal receptors) and produce a pain stimulus when a certain threshold is exceeded. Chemical stimuli, such as the acid content (pH value) in the cells or the metabolic products of the muscles, can also trigger pain. This leads to aching muscles.

#### ***Role of the fasciae***

For a long time, fasciae were regarded as an underlying layer of tissue that supported the gliding of muscles against each other and the restoring forces of the musculoskeletal system. This view has changed dramatically in recent years. Research results have shown that fasciae play a central role in both movement and the development of pain [20,21]. Fasciae are found throughout the body and form a larger surface area than the skin. Anatomical investigations were able to reveal a large number of sensory nerve fibres in the large thoracolumbar fascia [22,23]. Some of these nerve fibres are part of the pain-processing system [24]. In the process, improper strain and lack of exercise can lead to a change in the fascial structures, which in turn have a pain-promoting effect. On the other hand, healthy fasciae improve active mobility, coordinative abilities, body perception and can positively influence the sensation of pain.

#### ***Pain and movement***

Pain is a major factor in restricting the mobility. The movements of individual extremities can be restricted due to pain and this could considerably reduce the performance and activities of daily life in addition to existing disabilities. This is of central importance for one of the basic human needs, namely self-determination [25,26] or the preservation of personal room for manoeuvre. This applies in particular to Thalidomide victims [18].

On the other hand, various studies have shown that physical inactivity does not lead to pain relief in case of chronic pain. For example, in case of non-specific low back pain, bed rest either has no effect or delays healing and return to daily activities. Therefore, bed rest is not recommended for the treatment of non-specific low back pain [27].

A survey by the renowned Cochrane Institute in 2017 concluded that physical activity and exercise, with only minor adverse effects, can have a positive impact on the intensity of pain and physical function and thus improve quality of life [12].

Pain and movement influence each other. Therefore, both aspects should be considered equally when implementing appropriate therapy concepts.

#### **1.4 Pain situation of Thalidomide victims**

Various studies in recent years have clearly shown that chronic pain is much more common in Thalidomide victims than in the general population of this age group who are not affected.

According to Kruse and Ding-Greiner [2], pain occurred in 84.3% of 870 Thalidomide victims surveyed. In this study, 50% of respondents reported daily pain and 39% continuous pain. The intensity of the pain, divided into five grades (mild pain, moderate pain, severe pain and the most severe pain imaginable), was proportional to the severity of the damage, divided into four so-called damage severity groups.

In addition, it was shown that pain occurs mainly in the form of muscular tension in the back (78.6%), arms (43%) and legs (19.5%). It is caused by incorrect posture and uneven weight distribution on spinal column. This is very well illustrated by an example. *"In people with ocular palsy who move their heads while reading or working on a PC and thus follow the lines with their eyes."*

The authors stress that pain is a multifactorial process. This was clearly expressed in various interviews with those affected. For example, Thalidomide victims reported *that "the extent of stress or lack of rest periods and protection of the affected areas at work and at home plays an important role: Those who have the opportunity to determine for themselves how intensive daily stress is, who can use therapies to good effect and who are supported in everyday life have a good chance of developing less pain and discomfort in the long term and at the same time maintaining their physical performance."*

A further study commissioned by the Landeszentrum Gesundheit Nordrhein-Westfalen with a total of 202 respondents came to similar conclusions [18].

According to the study, over 62% of the participants had a high level of pain chronification. (Stage II-III according to Gerbershagen, see p. 36)

When differentiating the types of pain in nociceptive and neuropathic pain by means of [28] the painDETECT questionnaire, in half of those affected a neuropathic component with regard to pain was detected. This may indicate damage to the nerves, for example in nerve compression syndromes, or neurobiological mechanisms of pain chronification in central nervous [29] system.

More than 80% of the respondents reported neck pain followed by back pain as consequential damage caused by the prenatal malformations. In the extremities, shoulder pain (64.5%), knee pain (54.3%) and hip pain (54.3%) were most frequently reported.

With regard to pain, the authors come to the conclusion that painful consequential damage has become a dominant symptom in Thalidomide victims.

#### ***Nerve compression syndromes***

A study by the Thalidomide Trust with 20 participants [30] has shown that nerve compression syndromes, i.e. damage to individual nerves caused by pressure in anatomical constrictions, frequently occur in Thalidomide victims. Accordingly, 90 % of those examined had a nerve

compression syndrome. However, the validity of this study is limited by the small number of cases.

### **1.5 Biopsychosocial access to pain**

Pain, especially if it is chronic, is multidimensional. In addition to purely biological aspects of pain perception, i.e. the processing of stimuli in the nervous system, psychological factors such as anxiety and depression also have a major influence on the experience of pain. The pain processing system and the mental state influence each other. This influences our social network of relationships. Chronic pain, especially with restricted mobility, can have a negative impact on all areas of life (family, partner, friends, work, financial security, social integration).

Therefore, psychological and social aspects as well as medical-biological factors should be considered in the therapeutic access to people with chronic pain.

### **1.6 Control of pain**

Pain treatment or pain control should always be multimodal and interprofessional, because one pill or one form of therapy is usually not sufficient to successfully treat chronic pain.

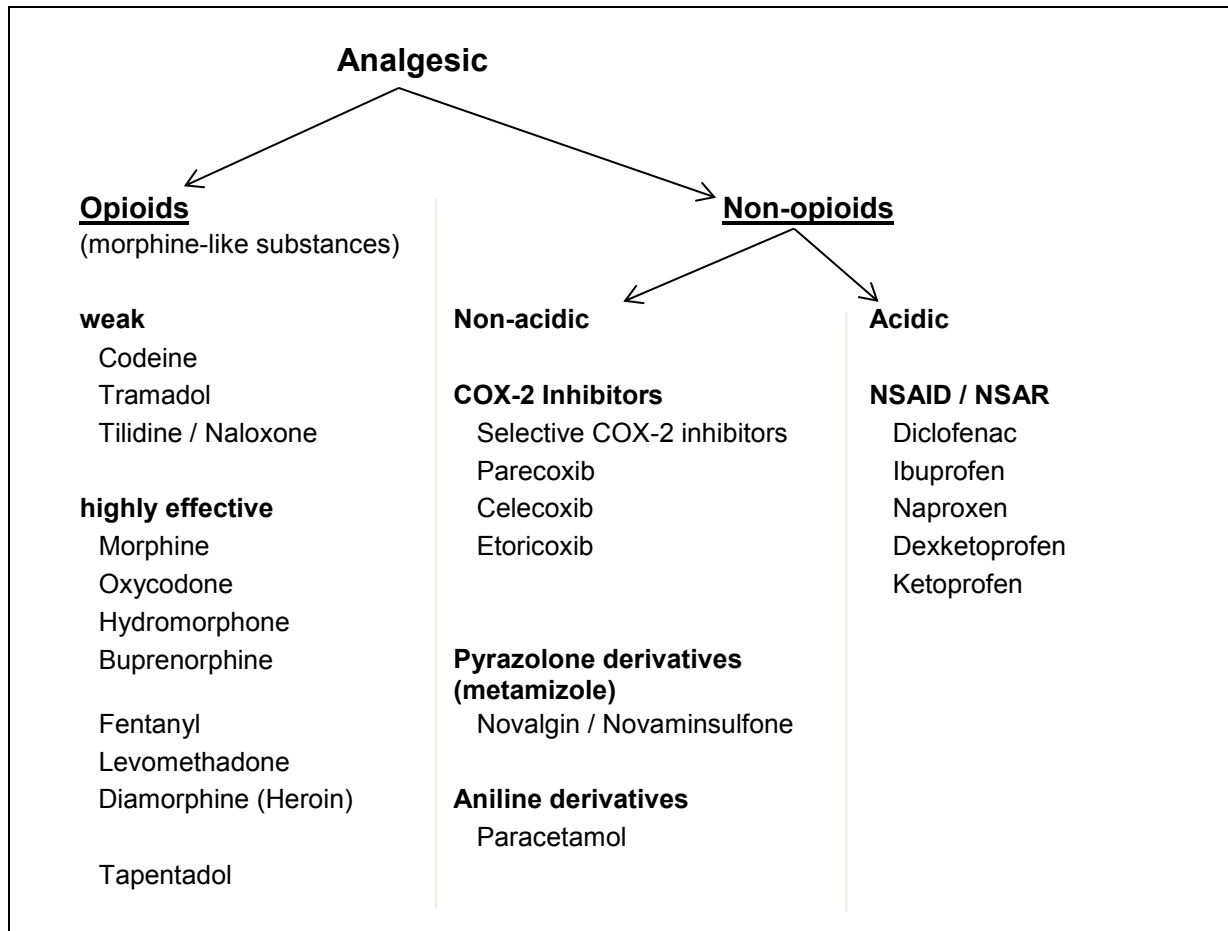
The first step is to consult together as to which goals can be achieved by which treatment. The goals are to maintain mobility and reduce pain. Pain control should be achieved through a combination of the following forms of therapy:

- Physiotherapy and physical activity
- Relaxation therapy
- Medications
- Psychotherapy

### ***Drugs for pain relief***

Drugs for pain therapy should be prescribed individually and combined if necessary. The selection of the individual substances should be based on the effect and any side effects that may occur. Drugs should not be given as monotherapy. Above all, they should not do any harm. In general, drugs should be administered orally.

Figure 3: Overview painkillers (analgesics)



Basically, a distinction is made between non-opioids and opioids (all substances that have a morphine-like effect). Both substance groups have peripheral as well as central effects. All non-opioids can cause significant side effects if used in the long-term, which require special medical attention.

### ***Non-opioids***

All non-opioids act by inhibiting inflammatory substances in the tissues.

Especially non-steroidal anti-inflammatory drugs (NSAIDs) and COX-2 inhibitor can lead to significant side effects and complications. Particular attention should therefore be paid to side effects, some of which are noticed late (kidney damage, high blood pressure), and contraindications.

### The main side effects of NSAIDs and COX-2 inhibitors

- Gastrointestinal tract: Stomach ulcers, bleeding (rarely due to COX-2 inhibitors)
- Kidneys: Acute interstitial nephritis, kidney failure
- Cardiovascular system: High blood pressure, heart failure

### Main contraindications for NSAIDs and COX-2 inhibitors

- Hypersensitivity to the active ingredients
- Pregnancy (3rd trimester)
- Gastroduodenal ulcer disease
- Chronic inflammatory bowel diseases
- Impaired renal function (GFR < 30 ml/min)
- Severe hepatic function disorder
- Heart failure NYHA stage III or IV
- Coronary heart disease

The concomitant intake of NSAIDs with corticosteroids significantly increases the risk of gastrointestinal ulcers. In addition, NSAIDs can increase the effect of anticoagulants.

The use of metamizole (dipyrone) can lead to blood formation disorders and life-threatening bone marrow suppression (agranulocytosis). However, these occur much more rarely than, for example, gastrointestinal side effects caused by NSAIDs.

Paracetamol is comparatively less effective and can lead to irreversible liver failure in case of overdose.

## ***Opioids***

Opioids are highly effective analgesics with a morphine-like structure. Since they have similar chemical properties as endogenous analgesic substances (endorphins), direct toxic effects on organs and tissue have not yet been described. This presents an advantage over non-opioids in long-term use, but when taken in moderate doses the analgesic effect on musculoskeletal pain is often less than expected. In a meta-analysis with a total of over 2400 patients, it was not possible to demonstrate the efficacy of opioids when used over a long time period (longer than 3 months) in chronic pain not caused by tumour [31].

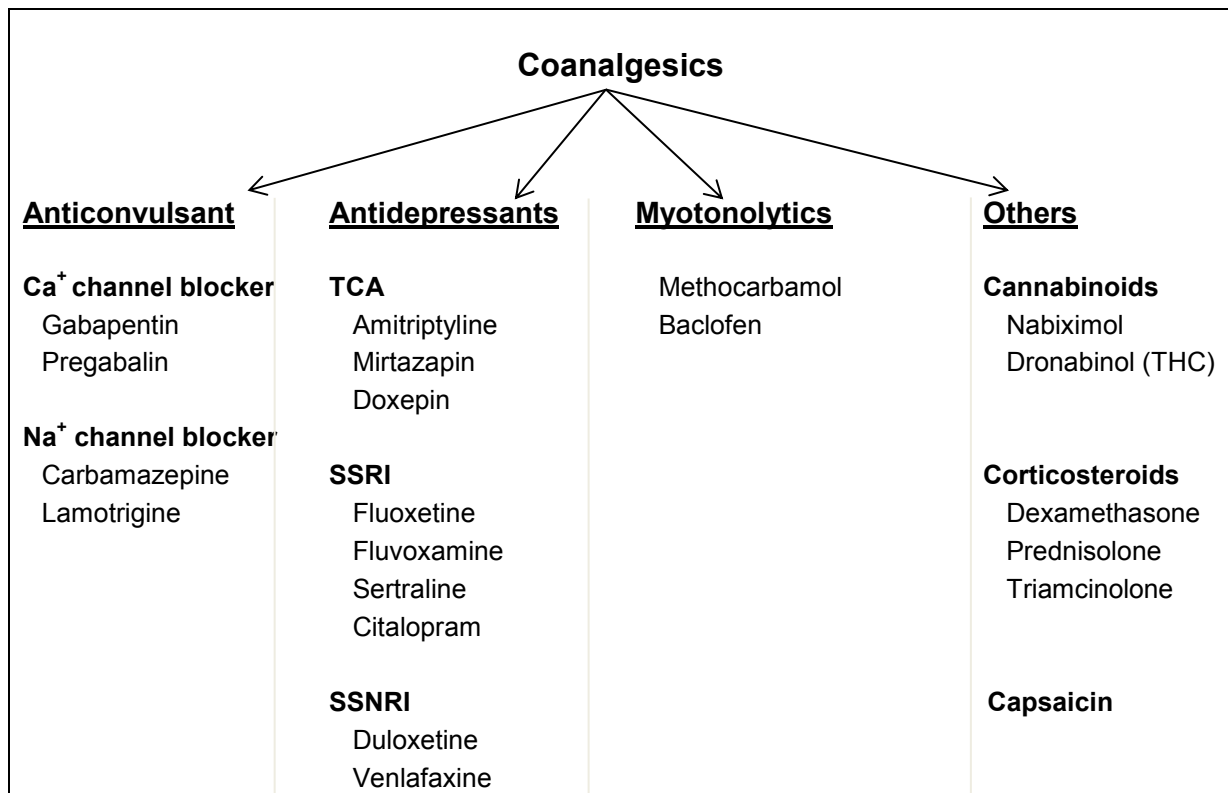
Typical side effects are fatigue, drowsiness, constipation, loss of libido, loss of effectiveness and adaptation. Particular care should be taken by patients with sleep apnoea syndrome (OSAS) because opioids can increase overnight hypoxia. Opioids should always be prescribed together with osmotically active laxatives (e.g. Macrogol).

The use of transdermal drug delivery systems (opioid patches) is critical because the slow release of the drug makes it much more difficult to control it than with oral administration. In addition, opioid patches should not be placed near children, as this has repeatedly resulted in acute poisoning through oral ingestion of used and discarded patches [32]. Some pain therapists believe that transdermal opioids should only be used in patients with severe swallowing disorders.

## ***Coanalgesics***

Coanalgesics are administered together with painkillers and can increase their effect.

Figure 4: Overview of coanalgesics



**Abbreviations:** TCA = Tricyclic antidepressants, SSRI = Selective serotonin reuptake inhibitors, SSNRI = Serotonin-Noradrenalin reuptake inhibitor, THC = Tetrahydrocannabinol, Substance of Cannabis Plants

Anticonvulsants and antidepressants are preferred for the treatment of neuropathic pain. Tricyclic antidepressants (TCA) and selective serotonin noradrenalin reuptake inhibitors (SSNRIs) have antidepressant and analgesic effects. However, the doses of TCA used for pain therapy are below the dose effective against depression.

Chronic neuropathic pain is more difficult to treat than pain due to other causes. The following treatment goals for neuropathic pain are generally considered realistic (Binder and Baron 2016):

- Pain reduction by 30-50%
- Improving sleep quality
- Improving quality of life
- Preservation of social activity
- Recovering and maintaining work/daily competences



## ***Practical recommendation for the therapy of chronic neuropathic pain [33]***

### Step 1: Diagnosis (Basis of therapy planning)

- Diagnosis of possible neuropathic pain?
- Diagnosis of mixed neuropathic-nociceptive pain?
- Diagnostic measures necessary to confirm diagnosis?

### Step 2: Causal therapy options

Is the cause of the underlying neuropathy known?

- If not, then perform diagnostics.
- If known, then utilise causal therapy options (e.g. optimise diabetes therapy, operative decompression in nerve compression, etc.).

### Step 3: Indication for drug therapy

- If causal therapy is inadequate or not immediately available or ineffective, early and adequate drug therapy should be indicated. A pain therapy should be started immediately if the patient suffers from pain in everyday life.

### Step 4: Therapy planning

- Evaluate previous pain therapy with regard to active substance, dose and duration of therapy (sufficiently long duration, sufficiently high dose?).
- Take comorbidities into account, including the possible side effects.
- Take co-medications into account, including their possible interactions.
- Take intolerances into account.
- Patient wishes with regard to avoidable side effects should be taken into account.

### Step 5: Patient information

- Formulate and coordinate therapy goals together.
- Specify the drugs used and explain their use as analgesics to the patient (strengthening medication adherence).
- Explain possible side effects and avoid interactions.
- Criteria for efficacy and ineffectiveness (slow onset of action, planned duration of therapy, need for titration).

## Step 6: Pharmacotherapy

First-line drugs include:

- Tricyclic antidepressants (TCAs).
- Selective serotonin noradrenaline reuptake inhibitors [SSNRI] (duloxetine).
- Anticonvulsants (gabapentin, pregabalin).
- Capsaicin high-dose patches.

### ***Myotonolytics (muscle relaxants).***

Myotonolytics are indicated for painful muscle spasms and extreme tension. Due to development of addiction (benzodiazepines) or serious side effects (flupirtine maleate), some of these drugs have been withdrawn from the market in recent years or can no longer be recommended. Myotonolytics can be prescribed if non-drug measures or the administration of non-opioid analgesics alone do not bring any improvement.

### ***Corticosteroids***

The use of corticosteroids is extremely limited due to their side effect spectrum and the mode of action. The following indications currently apply:

- Liver capsule pain, for example in tumour diseases
- Increased intracranial pressure in brain metastases
- Lymphedema
- Rheumatoid arthritis
- Joint pain (intra-articular injection)
- Neuropathic pain in tumour-induced nerve compression

### ***Cannabinoids***

The scientific data on the use of cannabinoids for pain therapy remains inconsistent.

*"Although a benefit could be found for chronic pain, it mainly refers to a slight reduction in pain. Furthermore, insufficient evidence can be found with regard to spasticity, which has so far been primarily investigated in MS or paraplegia". [34]*

Nevertheless, it can now be prescribed in Germany and the costs are covered by the health insurance companies under certain conditions. However, the hurdles are high, as the

medical service of the health insurance companies does not usually recommend the assumption of costs.

### Typical effects of cannabinoids

- psychotropic, euphoric
- calming
- antiemetic, appetite-stimulating
- muscle-relaxing
- vasodilating

The use of cannabinoids for pain therapy requires special monitoring by the physician who prescribes it. Binding agreements must be made and documented with the patient regarding intake and dosage. During the dose-finding phase, effects and possible side effects must be closely monitored. In case of insufficient effect or if side effects outweigh the benefits despite taking the drug in therapeutic dose range, the therapy must be stopped gradually.

The muscle relaxing effect of cannabinoids seems to be particularly advantageous in Thalidomide victims with limb malformations, so that treatment with cannabinoids as a healing attempt (trial treatment) is a therapy option.

Our own experience from the counselling sessions with thalidomide victims has shown that some patients undergoing therapy with dronabinol at a stable low dose report less muscular tension and reduction of pain. A small number of patients have stopped therapy due to side effects (confusion, drowsiness) and ineffectiveness.

Since no general prediction can be made about the therapeutic effect and any side effects that may occur, cannabinoids should be prescribed as an individual therapy trial that can be used if other myotonolytics are not effective enough. This is in line with a recommendation made by Canadian authors for family doctors [35].

### ***Invasive medicinal pain therapy***

Invasive pain therapy, i.e. the injection of medication at the site where the pain develops, should always be questioned critically solely because of possible complications (e.g. joint infections).

Repeated (serial) injections (facet infiltration, PRT) with corticosteroids and local anaesthetics for the treatment of chronic back pain usually do not lead to a sustained reduction of pain in the musculoskeletal system [36–38].

Some affected persons (individual cases in consultation hours with Thalidomide victims) experienced a significant pain reduction over a period of 3-5 months through a single injection of local anaesthetics and corticosteroids into the shoulder joints. This could be used for physiotherapy and active exercises.

## 1.7 Pain measurement and documentation

### ***Pain intensity - use of pain scales***

Since pain cannot be measured objectively, the assessment of pain intensity is carried out by means of self-assessment or external assessment on rank scales. The usual scales are the Visual Analogue Scale (VAS), the Numerical Rank Scale (NRS) and the Verbal Rating Scale (VRS). All scales have in common that the information shows a rank between 0 = no pain and 10 = strongest imaginable pain. In the English-speaking regions, pain is usually ranked between 0 and 100. However, these scales only apply to adults who are not cognitively impaired. For people with dementia, so-called external rating scales are used. For example, BESD by the German Pain Society or the DOLOPLUS- 2-Short.

Regular recording and documentation of pain intensity is essential for assessing chronic pain and the quality of treatment. The intensity of pain should be assessed several times a day as part of the initial assessment, at the start of therapy and in case of any change in therapy. If the patient is in a stable state, the pain intensity can be assessed during the follow-up visit with the attending physician.

### ***Pain chronification.***

Chronification of pain is an expression used to describe the increasing independence of permanent pain with an effect on psychological and social well-being. In order to assess the severity of a chronic pain disorder in the German-speaking areas, the Mainzer Stadienmodell (stage model) of pain chronification according to Gerbershagen has [39,40] proven to be suitable.

**Table 4: Pain chronification according to Gerbershagen**

Stage I	Pain (sub-)/acute, changing intensity, appropriate medication, less frequent change of doctor, stable coping strategy
Stage II	Continuous pain, increasing spread, multilocalisation, mostly inappropriate medication, frequent change of doctor, disruption of coping strategies
Stage III	Persistent pain, everywhere, nothing helps, doctor-hopping, complete helplessness, only emergency doctor is appropriate

## 1.8 Multimodal treatment concept

Chronic pain disorders with physical, psychological and social consequences require a therapy plan that is adjusted in terms of content and time by several disciplines and professional groups. This form of organisation is called interdisciplinary multimodal pain therapy. The therapy includes physically and psychologically activating and relaxing

psychotherapeutic procedures according to the treatment plan. The therapy goals are discussed with the patient in an interdisciplinary team. [41]

Figure 5: Multimodal pain therapy (modified according to Stork)



## **8 Pain and movement from the point of view of physiotherapy**

*Dagmar Seeger*

The complexity of pain is also seen in physiotherapy. Accordingly, the physiotherapeutic treatment is complex and takes into account the various factors of pain development and persistence. Nowadays, physiotherapy is often part of interdisciplinary and multimodal treatment concepts, which include active exercises, movements and the relation to everyday life. Here, attention is paid both to maintaining mobility and balance and measures are developed to maintain or restore the ability to recover and regulate.

Exercise programmes, health-oriented concepts [42] with regard to salutogenesis and "back to work", improving the quality of life instead of thinking about the causes of illness, have become more and more important in recent years in the treatment of the most widespread disease: back pain [43] and pain in general. Concepts that can bring about a change in behaviour appear to be particularly successful. The focus is on the goal to positively change the experience of pain and impairment through learning to succeed (operant conditioning). In addition to building up functional reserves for mobility, these concepts are also particularly suitable for the treatment of chronic pain, which lasts longer and is influenced by various factors. People learn constantly during their daily life. Success is particularly supported by new and unexpected stimuli. Active movement strategies (new stimuli: such as new movements, moving to music, moving with new material, small devices) are better suited than passive strategies to reprogram and overwrite the so-called "pain memory" of the past [44]. The concept of pain physiology takes into account the pain mechanisms, the general conditions of a person and their effects on the sensation of pain. The evaluation of pain, thoughts and feelings play an important role here (see Chapter 6 and 7.1).

It is important to know that information regarding pain caused by injury is transmitted to the brain by certain reporting units (nociceptors) so that the tissue is immobilised and can heal. Inflammatory, mechanical stimuli and insufficient blood circulation (ischaemia) can cause pain. Usually pain alleviates on its own. If the pain persists and healing process is long over, other factors play a role. Here the pain becomes independent and is generated, intensified or alleviated at the so-called "processing level". There are also certain signs and underlying diseases that favour a stronger sensation of pain (weak immune system, autoimmune diseases, experience of pain in childhood) without causing greater damage. This is the response of the brain itself. Factors at the processing level can be influenced and the sensation of pain can be positively influenced. "Processing level" means that the sensation of pain is negatively influenced by negative thoughts ("...how is everything supposed to go on...") and feelings ("...I am very worried about the future..."). Confidence and positive plans reassure and support positive development.

For example, the principle of "graded activity" can be mentioned here as an example of systematic planning of movement tasks from everyday life that is adapted to individual requirements [45]. It is an individual procedure with systematic increase. The intensity of the movement tasks is determined by the functional tests performed at the beginning. What do

you need for your everyday life? What are you not so good at? Then proceed as follows: First check to what extent can you perform an activity:

e.g. sorting plates, sitting upright, walking

- Frequency (repetitions),
- Duration (time in seconds, minutes, hours),
- Distance (meters, centimetres, time)

This will show you your stress limit. Select 50-75% of this and start exercising. Suppose you can sit upright for a maximum of 10 minutes, but would like to sit for 30 minutes. That depends on your target. The training plan then indicates that you start by sitting upright for 5 minutes. Do this 3-4x/day for 2-3 days. Then increase by 1 minute or 30 seconds, if 1 minute is too much. After another 2-3 days, you increase again. Until you have reached the desired target. The important thing is that you stick to this plan. Do not sit for a long period of time because it is going well. Only sit for as long as the plan says. The defined break is part of the training plan. You quit while you are still feeling fine. This develops your stress limit and it slowly increases as you train below the stress limit. There is no overstraining or overexertion while exercising. In everyday life, however, this is unfortunately unavoidable. It should be different when you are exercising. A break is taken here even though it is still possible to go on. In everyday life, when you overstrain yourself, you require a balancing movement so that the structures can recover and a break so that the entire body can come to rest.

Training should be better kept submaximal in case of pain. Even if you are interested in sporting activities (see Chapter 2). The individually selected exercises (e.g. endurance and strength training, lifting, walking, jogging, swimming, gymnastics, fitness training, bicycle ergometer) should not be carried out up to the tolerance limit in case of pain, but should be rather performed as described above. The pauses between the exercises are also part of the training program and support learning for success.

Pain physiotherapists use various instruments for evaluation and course monitoring taking into account various influencing factors and regulatory circuits of pain. Here are some examples:

- Assessment of motor test tasks (change of position, lifting, carrying, bending down, sitting, repetition of movements)
- Measurement of performance to assess the capability according to objective
- Functional Ability Questionnaire - Back (FFbH-R), for spinal pain
- Progressive Isoinertial Lifting Evaluation, (PILE Test)
- Activities of Daily Living [46], Patient-Specific Function Scale (PSFS) (Heldmann)
- Occupation- and daily life-specific survey
- Assessment of the stress profile (work, leisure time)

### ***Where, when and why does it hurt?***

Classical causes of musculoskeletal pain that can be treated with physiotherapeutic measures:

- Muscular tensions
- Weakening of the muscles due to degeneration/wear of the joints and reaction of the soft tissues to it
- Injuries / diseases (accidents / operations), promote healing
- Risk of chronification - Prevention of deterioration and other ways of managing pain and impairment

The following pain intensifying and alleviating factors can influence pain

- Stress / Rest
- Emotional stress / balance
- Catastrophic thoughts and beliefs require strengthening of confidence
- Fears and insecurity/confidence in the body's ability to regulate itself

### ***Specific characteristics due to pain in childhood***

Severe or persistent pain in children (of any age) can be a factor for increased pain experience in adulthood. This underlines the importance of pain detection and management in new-born infants and a different approach to pain control in children and adolescents. A high percentage of people with thalidomide embryopathy have experienced pain during childhood. Here it is important to know that the nervous system reacts more easily and quickly to pain stimuli, and can even trigger it by itself, since certain sensitivity reaction (sensitisation) to pain conduction has already occurred. This does not mean that the organism is then particularly ill. Knowledge about pain mechanisms and sensitisation processes shows the need for confident strategies and a systematic build-up of resilience. It is not the structures that are defective, rather the quick reaction of system particularly to stimuli from the structures. It's treatable.

### ***Pain in old age***

Here, too, people with thalidomide embryopathy are particularly affected as they reach the phase of old age. Experts agree that there are considerable deficits in the recognition of pain, assessment of pain, as well as in management of pain of older people, especially those with dementia. Elderly people with an increased need for support and mental disabilities require special attention and assessment and treatment of pain. (Safety and stability with the longest possible self-preservation of everyday activities are the primary goals here. Here the sentence "Use it or lose it" applies - "Use your body or lose it". Here, too, the following applies: maintain or even re-conquer everyday life in small steps.



### **What do we need in old age?**

*"Old age is only for the brave" (J. Fuchsberger, German actor)*

We need courage to move forward and the resources to achieve greatest possible self-sufficiency. These are:

- Body awareness for good feeling and good function
- Mobility for the necessary movements of everyday life
- Strength for the strenuous tasks of everyday life
- Creativity in problem solving - solution-oriented thinking
- Confidence, trust, security for the coming years
- Seeing, hearing, touching, feeling or alternatives.
- The courage to seek and accept help.

### **Therapy concepts**

About 80-90 % of physiotherapeutic treatments are being used "as usual" in 2018. These correspond to the specifications of the German drug catalogue with given techniques and defined number. The WHO criteria classify this at the structural and functional level. Physiotherapists are very well versed in this field and can offer a variety of techniques that can be applied individually. However, WHO also makes provisions for the level of activities of a person as well as participation in social life. The goal should be defined here. Occupational therapists are very well trained here. At the same time, pain therapy measures can also be used:

From a pain-physiotherapeutic point of view, newer treatment concepts should be increasingly implemented in accordance with modern pain therapy findings:

- Increased capacity for everyday activities through "Graded Activity" (operant conditioning, small steps)
- Confrontation with anxiety-related movements or activities. Concepts based on "Graded exposure" are also suitable for this (requires good expertise).
- Health sports in interdisciplinary treatment programmes (physiotherapists, sports therapists, occupational therapists, psychologists, physicians) with the aim of continuing them in everyday life, and recommendations with regard to the continuation of sports in everyday life
- Multimodal concepts based on structure, function and activity, including patient education (disease-specific)
- Multimodal treatment programmes include inpatient, outpatient and day clinics with a target [47] (This programme should be specially developed for people with thalidomide embryopathy)

In case of pain, it is important to know which pain mechanism is causing the pain and how it can be treated. Centrally generated pain is characterised by anxiety and uncertainty as well as negative thoughts. These can be well managed through education and information. Pain caused by muscular tension can be specifically and repeatedly treated and weak muscles trained specifically. In such a case, every now and then one still suffers from pain, but it can be dealt with differently and in a better way. So, it is possible to follow a confident and optimistic path leading straight to old age.

#### Practical recommendations

- In the case of acute pain, find a diagnosis, if possible, and treat the cause. Acute pain often goes away on its own.
- In case of chronic pain, rule out serious causes and understand the pain mechanism.
- Formulate goal - where do I want to go? What exactly should get better?
- Train body awareness for positive body sensation.
- Find relaxation techniques, try them out, train regularly.
- Activate the senses (seeing, hearing, feeling, smelling, tasting).
- Within a comfortable zone, move whatever is mobile (joints, muscles) and maintain or expand the range of mobility
- Muscle building and endurance training, small steps.
- Search for (sporting) activities that convey fun and enjoyment
- Work actively. Define new goals for daily life activities, and gradually pursue them. Systematically pursue these goals.
- Use mental images and positive thoughts, as mental training can positively influence the regulation of pain.

#### ***Additional Information***

Pain in children and adolescents: <https://www.dgss.org/patienteninformationen/besonderheiten-bei-schmerz/schmerz-bei-kindern/>

<https://www.youtube.com/watch?v=KpJfixYgBrw&list=PLiFJezQX8KW3-bZ2dL6Hhpwli6x3LQ3W->

Pain in old age:

<https://www.physiotherapeuten.de/chronischer-schmerz-bei-senioren/#.W9nMoDExmUk>

<https://www.dgss.org/die-gesellschaft/arbeitskreise/schmerz-und-alter/downloads/>

## 9 Therapy experiences - Conversation with the physiotherapist Jenny Schiller

**Note:** The article/interview first appeared on the Contergan-Infoportal CIP of the Contergan Foundation for Handicapped Persons in Cologne. More information can be found on [www.contergan-infoportal.de](http://www.contergan-infoportal.de)<<http://www.contergan-infoportal.de>>

**Contergan Infoportal (CIP):** Mrs. Schiller, what are the classic pain patterns with which Thalidomide victims come to you?

**Jenny Schiller:** It differs from individual to individual. I just saw a patient with no arms and only fingertips on her shoulders. She mainly suffered from pain in the shoulder and neck area. In her everyday life, she has to bend her head very far to put on her glasses. She bends down and supports her fingers with her knees to put on her glasses. This involves consequences. Pain in shoulder and neck is very often a distinct pain pattern, which our Thalidomide victims suffer from. What makes matters worse is that all our thalidomide victims are the same age, about mid 50s, and at this age the intervertebral disc is often injured. I am afraid a lot of people suffer from this injury at that age. But the many deviating movements that Thalidomide victims have to perform are now taking their toll. Intervertebral discs, back pain, problems with the lower back ... the spectrum of problem areas and pain is wide. Thalidomide victims often have - due to their deviating movements - a hypermobile hip joint and a very mobile spine, because they have to perform movements that involve lateral inclination, bending and straightening up. As physiotherapists, we have to stabilise and also support muscle development in order to restabilise the patients. In other words, classic age-related topics in orthopaedics and the increased occurrence of consequential damage due to excessive strain, which is added to the primary damage. All in all, this is a very complex topic.

**CIP:** With which exercises or therapeutic approaches do you try to provide relief and respond to challenges?

**Jenny Schiller:** It always depends on what the patient comes with. Before starting the therapy, we define the main problem together. What bothers a Thalidomide victim the most? Or, what restricts him the most in everyday life. In addition, there is the ICF model, where one looks at the structural level, which joint or which muscle might be causing the pain or which ligaments are overstretched. But then we also look together at what this means in concrete terms for the person concerned in everyday life, what restrictions it causes and how it limits the people to take part in everyday things. Then we have to decide which therapy approaches could help the person concerned achieve relief in everyday life. It is also important to see what is the main focus. Restrictions in mobility or the pain. If the thalidomide victim is mainly affected by pain, then my joint techniques are naturally aimed at pain relief. You can think of it as a modular system. Then, for example, I look for a small amplitude and slightly work against the resistance in order to lower the pain or the sensation of pain. But when a patient comes to me and says, 'I feel so stiff here and I cannot bend further, then I

check, for example, where I can find firmer structures in the spine and where is the resistance that we can work on to make the patient more mobile in this segment. So, the objective always depends on the problem that the person brings along. That is why such a treatment always starts with a discussion and a diagnosis: What does a person bring along? What is his current condition? Which problem bothers him the most? This then determines the further course of action.

**CIP:** And if pain is the main problem?

**Jenny Schiller:** Then first of all I use a pain-relieving technique. This involves the exertion of a small intensity and a small amplitude (extent of the effect, editor's note) on the joint. This can be done by, for example, a soft tissue technique (muscle and deep tissue massages, editor's note), which is always very popular. Our patients also love warmth, e.g. a hot roller, because this loosens their muscles for the time being. This is already perceived as beneficial and pain-relieving by those affected. In addition, it creates trust with the therapist. That is very important. Because you have to be able to let go and just entrust yourself to the therapist who treats you and lays hands on you. After successfully performing the above mentioned preparatory actions, we can continue with other measures. Then it is necessary to determine, for example, how the bones can be moved relative to each other, the individual vertebral bodies and so on.

**CIP:** After the use of a relaxing roller, the larger "guns" come into play.

**Jenny Schiller:** (Laughs) Other ... not bigger. Then we look concretely at which movements we can influence positively by means of our joint techniques. Manual therapy always refers to joints, which can be moved relative to each other. And depending on the degree of intensity, I either influence the pain, mobility or stiffness that I can manually remove. The intensity can be increased depending on the problem. A very high intensity can be applied in the manipulation of the joints, which is also commonly described as "correction work".

**CIP:** You mentioned that some approaches or therapies are more popular. So, there is such a thing as favourites among those affected?

**Jenny Schiller:** What always goes down well are passive measures, application of heat or working on the muscles in form of a classical massage or lateral stretching. A selective lateral stretch is a bit more unpleasant, but some patients also like that because you can feel that it quickly brings relief. But that is not all in manual therapy. We must try to bring the person back into symmetry and also activate it. This includes above all the muscles, which it does not continuously use for the movements in his everyday life. And this is where it becomes exhausting for our patients. But we also have to make this look attractive to them so that they can participate well in these efforts with their own exercises. That is why we have our groups. As therapists in group therapy, we can also give the patients good instructions for self-exercises. We don't just have to give them in the individual exercises. It is important that the patients are always given something that they could make use of at home

when they are alone. Always with the aim of providing more relief for your body while moving, to stand up in a better way etc.

**CIP:** Because the success of rehab doesn't last forever, does it?

**Jenny Schiller:** No, it's constant work. The relief often lasts only for a certain period of time. How long it lasts depends on the individual pain patterns. That is why some patients come to us again and again. The fact is, we can't take away the basic problem. It persists. Therefore, constant work is required to treat symptoms and muscular imbalances, which remain there and cannot be healed completely. Our patients have to keep at it even after rehab. But that's what our patients actually do. They also have their treatment sessions at home, where they continuously work on the problems together with the local therapists.

**CIP:** What is the particular advantage of inpatient rehabilitation?

**Jenny Schiller:** Rehab is a more comprehensive and intensive form of treatment. The affected persons usually come to us for 3 - 4 weeks and every day they undergo intensive individual physiotherapy and group treatment in the water and on ground, if necessary applications with electricity, massages, infrared applications, lymph drainage ... and ergotherapy rounds off the compact programme. At home, you continue your everyday routine. The patients go for physiotherapy once or twice a week and often only have 20 minutes in the practice, and then they leave again. In rehab, the intensity is simply greater and we have the chance, for example, to effectively interrupt pain mechanisms and to start moving freely again and train our own body feeling. We can't do that in 20 minutes. Here in rehab I can work intensively with my patients. In this way, we can find out together if the person moves too little and perhaps too much, and then identify, apply and practice targeted solutions. That's what rehab can do. It is simply a more intensive overall package, only to return to everyday life and say that I will continue to work on it and I will try to follow these meaningful instructions. I think it's a constant process of change and adaptation. You learn with each other and from each other. In addition to primary damage, there is consequential damage and signs of ageing or the normal wear and tear that every body experiences over the years. That doesn't make it any easier for our patients.

**CIP:** Isn't it difficult to have to completely change a behaviour that has been practiced for a long time and which has helped your patients in their everyday life? And to maintain this consistently?

**Jenny Schiller:** We usually do not show big changes. Sometimes just little tricks. I think the patients are already able to implement this quite well. For example, a thalidomide victim who has very short arms will not be able to bend backwards as well as someone who has all extremities. Here we show them alternatives and above all recommend obvious things. For example, they might want to consider moving several small portions when shopping, e.g. from the trunk into the house. They should not lift and carry too many and too heavy things. These are everyday small things, which have a big influence. And you can practice them. But

there is always a way and sometimes it takes time to learn. Human beings are creatures of habit and it is often difficult for us to accept changes, but in small steps they are already accepted by the patients and also considered to be helpful.

**CIP:** Are there any exercises that the patients can do at home?

**Jenny Schiller:** Of course. We prepare different exercises in individual physiotherapy. In addition, we also have printouts which we give to the patients. Unfortunately, most of them refer to complete body exercises. Therefore, I prefer that we practice it together so that the patient knows how the exercise is done correctly and then we simply repeat and practice it. Sometimes I give my patients stick figures painted by me as a reminder of the subject "How did I actually want to do this in my exercise?". Inflatable seat cushions are also helpful for exercises at home. They look like a round disk. There's air in it and when you sit on it, you're actually constantly challenged to balance your position because the air in the pillow moves back and forth. This allows the patients to work on the deep postural muscles in the back and spine. This is done without constantly thinking "Oh, I gotta exercise now." You simply practice it while sitting and integrate it into your everyday life. What is important is consistency and continuity in exercise, because we humans often only act when it pinches and then quickly stop when it no longer pinches.

**CIP:** Based on your experience, do you have any practical tips that patients should follow?

**Jenny Schiller:** What we often see in our patients, not only thalidomide victims, are possibilities for optimisation when standing. When someone stands, it usually stands with its knees bent and its upper body hung a little backwards into the hip. And here we point out again and again: When standing, make sure that you have good ground contact with the sole of your foot and that your knees are slightly bent. Then the rest of the body will almost straighten up by itself during the activity. Then the shoulders can also relax and hang down again. But when I stand on a knee that is completely bent, there is a great strain on the cartilage and the ligaments. My pelvis slides forward and my head - because I still want to see something - slips forward. Nothing is in balance anymore. I'm really stuck in the ligaments and cartilage structures, which doesn't do my joints any good. It is of course also comfortable for the moment, but it exerts a lot of strain on the joint structures. So, if I want to take care of my body, I stand in a flexible position with slightly bent knees and legs about hip width apart. A physiologically optimal posture when standing also prevents back pain. In addition, I find myself in a position where I can always react to my environment, for example when someone comes and joins me. With my knee completely bent, I can no longer react adequately. We see that a lot. And I also like to give my patients the following tip: When they are standing, e.g. next to kitchen countertops, traffic lights or wherever, they should simply imagine that they are listening to a good song. Just imagine internally, others don't even have to see from the outside. But if you're in a good mood and are listening to a nice song, then you'll swing along. And you don't have a bent joint. It's completely automatic. You're welcome to try it sometime. It works!

**CIP:** Well, some Thalidomide victims are dependent on a wheelchair.

**Jenny Schiller:** You can do that in a wheelchair, too. However, for patients who sit in a wheelchair, there is unfortunately more passiveness involved, e.g. due to the backrest, pads and additional mobility restrictions. But even here it is important to bring as many variations as possible into sitting in a wheelchair. Such as detaching yourself from the backrest every now and then, putting another cushion in the wheelchair and simply looking for other variants. But yes, it's definitely harder to stay active in the wheelchair. You can't say that in a beautiful way either.

However, there are also possibilities here, e.g. to activate the upper body while sitting on the seat. If, for example, a patient cannot exercise properly on the device because he or she does not have or cannot take the position of the elbow or hand that he or she needs, then one has to find variants and that is what we as therapists are here to help with. We can modify exercises or work against therapeutic resistances, if we ourselves put our hands to it. The aim here is to develop a programme with which the thalidomide victim can be meaningfully challenged and supported. What works best has to be found out together with the patient. That's one way, too. I always have to see to what extent the patient is willing to work together with the therapist and when it simply becomes too much for it. It would be nice if I only had to lay my hand to solve all the problems. This may also be the reason why some patients prefer passive applications. But if you want to achieve something in the long run or maintain an improvement, you have to stay active..

That is why patients should incorporate as much exercise as possible into their daily lives, even when they are not doing so well. We want to preserve the mobility and if I'm not doing so well, then I perform the movement carefully and don't carry 5 milk bags in addition. Better to perform a movement more often and with a low load. Always stay active, because maintaining activity is only possible by staying active. This also applies to the muscles. We preserve them by using them, otherwise we lose them bit by bit.

**CIP:** What do you have to pay special attention to when dealing with thalidomide victims?

**Jenny Schiller:** I once brought various text books. All technical literature and our documents always refer to complete joints. One always starts from a healthy, complete body and searches for disabilities within a joint, outside in the nerve elasticity or also the muscle elasticity. The great task for us is then to see how these textbook guidelines can be applied to the Thalidomide victim, because it does not, for example, have a complete joint socket in the shoulder.

**CIP:** In a conversation with Dr. Graf, he referred to the "trial and error" approach, which you tried to use in the 1980s to further promote the treatment of thalidomide victims. If a therapy idea did not work, it was discarded. If something worked, it was developed further. It seems that not much has changed to this day.

**Jenny Schiller:** Yes, if something works, then you continue with it. This, too, is a path we take together. Checking together with the patient, also in terms of intensity, how far we can

mobilise e.g. a shoulder joint. If someone comes this far (points to a spot on the cheek with their arm) and wants to be able to scratch behind the ear, then it is not always part of manual therapy to say, I will mobilise till I can touch the back of ear. In individual cases, this may lead to an additional impairment of this incomplete joint. Then we have gained nothing with these 3 centimetres more freedom of movement, because it resulted in the development of pain. Well, you have to weigh the benefits and disadvantages very carefully.

And even if nothing has changed in the textbooks. We have gained a lot of experience by working with thalidomide victims for a long time and now know more precisely what works and what does not. But - despite the many years of experience - every year we also break new ground, e.g. through the combination of primary damage, consequential damage and signs of age-related wear and tear. Here we have to keep looking again and again at how we can make progress in the new situation with the resources we have. But we have to slowly see, how far can we go, what can people tolerate, the intensity with which I can use this joint and what is the body's response to it.

**CIP:** Which techniques do you use?

**Jenny Schiller:** Our manual therapy comprises of the following techniques:

- Soft tissue techniques (muscle and deep tissue massages)
- Heat applications, e.g. hot roller to loosen the muscles first, infrared cabins (heat and loosening),
- Cryotherapy (cold air therapy, e.g. for scars, is very beneficial for those who have just undergone surgery and helps with tissue irritation).
- Two and four chambered galvanic bath (applications using electricity),
- Kinesiotape/Taping or also
- Group therapies on ground and in water.

Manual therapy mainly includes:

- Joint techniques to relieve pain and improve mobility,
- Muscle techniques to stabilise the extent of movement, as well as the
- Nerve mobilisation.

Nerve mobilisation depends on whether a nerve is irritated or not. I can only mobilise a nerve if it is not extremely irritated. Otherwise, I can try to gently produce a movement and to stimulate the metabolism in the system to a very small extent.

In general, we try to find out where did the pain come from? Is it intra-articular (inside a joint, editor's note) or extra-articular (outside a joint, editor's note)? Is it joint pain, soft tissue pain or nerve pain? Depending on the diagnosis, action is then taken. But if, for example, I have a



very irritated shoulder, which is already extremely painful when I start to lift the arm, then achieving mobility is only the second priority. First, we use a very gentle joint technique, with a small amplitude and a low intensity. A mini joint mobilisation is then often the first step to relieve the pain. And only when I succeed, I can go a little further and check whether it works at a higher position of an arm movement. It's all a question of dosage. Start with a very low intensity and a small amplitude and then see if you can stabilise this condition of the joint to make it more resilient. And only when the pain is no longer the main issue, you can start to work actively with the arm. Because nobody likes to work against pain. This is a natural inhibition threshold. For this reason, manual therapy also includes pronounced knowledge of the therapists about wound healing mechanisms and pain mechanisms. I need to know how much strain I can place on the joint. The intensity of treatment depends on this. And this is all the more important in patients affected by thalidomide because their joint structures are not similar to those of "healthy" patients or the ones in textbooks. We must then simply adapt our treatment techniques and, in individual cases, weigh up our approach in the overall context. If someone says that I can touch the side of my head and that doesn't bother me at all, but I definitely want to get to the back of my head, then we can test it in a trial treatment. But it can also happen that the next day or the day after that we have to say that we would rather not allow it. Even the usual lifting of hand was painful and the maintenance of the existing mobility of the patients is much more important to us than moving the hand two centimetres further back. That would prove to be too costly, especially in presence of pain.

**CIP:** You mentioned earlier that sometimes you would give your patients line drawings as a reminder for the exercises at home. How can we imagine the drawings to be?

**Jenny Schiller:** The drawings are actually very simple. These are just simple stick figures that I use, because there are no special sheets for exercises for Thalidomide victims. Here is an example (numbers added by editorial staff):

Figure 6: Drawing by Jenny Schiller for visualisation of exercise



If I want to show a patient with short arms how to get from a sitting to a standing position as part of an exercise, my first step would be to move the arms forward. Next step would then be to tilt the patients upper body back and forth from the seat in a nice straight line. The patient is always ordered to move his own chin down. I make an arrow like this here (1), then he knows, chin needs to be moved downwards. Then he should move his upper body back and forth (2) in this upright position. Now he has already activated his back muscles once. If this works well, I can combine it with a rotation of the upper body (3). Then, if the seat is high enough, I can ask the patient to move one foot backward and one foot forward (4). Its arms are not so long in this case ... but if it wants to use them, it can lift them up and down. The spine also ensures stabilisation of the patient because at the moment when I actively mobilise body parts or move them, other areas are to be stabilised. And then, for example, we ask the patient to stand up from this step position. It is a lot easier than standing with both feet parallel. You experience more of a rotating and swinging movement. In order to increase the difficulty of the exercise even further, the patients can place this inflatable seat cushion on the stool again and then sit on it. Due to the unstable base, they are required to constantly balance themselves. The continuous effort to correct posture makes this even more difficult. There are little tools. They don't cost much, don't take up much space, but they are very effective.

We recently saw a severely affected woman without legs and arms. We did a lot of work on the trunk with her and practiced the "bum walk". We asked her to first sit upright (pointed towards the couch). Then we practiced with her how to maintain the upright position and shift the weight so that she is able to move further and turn around at least on the floor. I've still got my heels here to support me. However, this is hard work for the patients. Without

supporting heels the risk of falling over is greater, because the levers are missing. Therefore, a lot of work is needed on the trunk. This would be again done through therapeutic resistance e.g. in the shoulder blade. You already notice, that was only one minute, if you do that over a longer period of time, it just adds up ... we call this temporal and spatial summation ... and it's hard work. The resistance in the muscle and thus also the upright position of the trunk is strengthened. But they won't see much in my drawing. That's why I don't do it.

For all exercises, here and also at home the following applies: If I want to achieve a sustainable improvement, then I have to stay active, even if it is sometimes difficult for me. This is the price you have to pay to achieve pain relief or improved mobility.

**CIP:** Thank you for speaking with us.

## 10 Anatomical features of the shoulder

*Jan Schulte-Hillen*

Thalidomide victims with damage to the upper extremity very often have a partially or completely different anatomy of the skeletal parts as well as of the musculo-skeletal system and the vascular nerve fibres. The differences within the group of victims are enormous. Some patients have a shoulder joint at the time of birth in which the humeral head is not connected to the shoulder blade (luxation or subluxation).

This can easily lead to misinterpretations in case of a visit to a doctor due to shoulder complaints that are not caused by an acute injury. In such a case, after the x-ray is performed, an attempt is then made to put the shoulder back in the supposedly correct position (shoulder reposition), and this mostly leads to increased discomfort and injuries.

**Figure 7: Damage to the shoulder caused by thalidomide. A) Dysplasia of the humeral head (Merkle et al. BMC Musculoskeletal Disorders (2016) 17:185) B) Removal of anatomical joint structures (Case courtesy of Henrik Borgesen, Radiopaedia.org)**



# 11 Maintaining mobility of the shoulder from an orthopaedic point of view

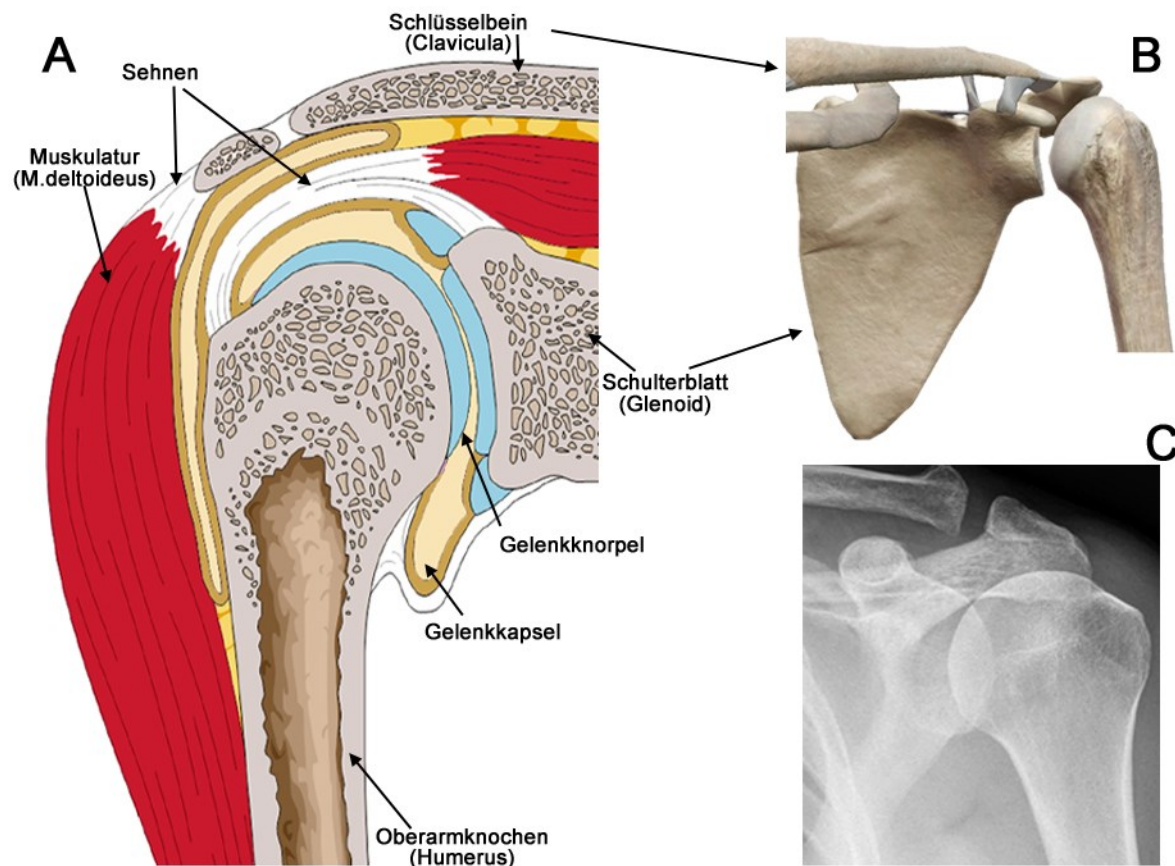
Mathias Weber

Thalidomide victims more often suffer from damage to the upper extremity than to the lower extremity. The shoulder joint plays a key role in life activities and in leading an independent life. It is assumed that osteoarthritis of the shoulder joint leads to increased problems for many patients.

## Anatomy of the shoulder joint

The shoulder joint is a so-called ball joint and consists of the humerus and the shoulder blade. The special feature of the shoulder joint is the low bony guide and stabilisation given by the surrounding muscles, the so-called rotator cuff. This special structure ensures a better range of motion in the shoulder joint compared to all other joints.

Figure 8: Normal anatomy of the shoulder joint. A) Structure of the shoulder joint, B) Joint forming bones, C) X-ray anatomy, (Case courtesy of Prof Frank Gaillard, Radiopaedia.org)



### Typical damage to the shoulder in people affected by thalidomide

- Malformations of the skeletal parts in the joint (shoulder dysplasia).
- Subluxation and luxation, the humeral head is not connected to the joint.
- Absence of the shoulder joint.

As a result of the malformation, the joint is subject to wear and tear (arthrosis) as a result of constant excessive strain on the joint cartilage. This in turn leads to pain and reduced mobility. Since the upper extremities form a functional unit together with the cervical spine and the muscles, this can cause pain in a very large number of thalidomide victims: Painful tension in the shoulder-neck area.

### ***Treatment options***

There are conservative and operative forms of treatment. If possible, conservative therapy should always be preferred over operative therapy. This does not apply to injuries and fractures, which are usually better treated surgically.

### Objectives of conservative therapy

- Pain relief
- Improvement of mobility
- Maintaining self-reliance
- Avoiding or delaying an operation

### Established treatment methods

- Drug therapy
- Physical therapy
- Acupuncture
- Autogenic training
- Provision of aids

It has been shown that physiotherapy can achieve the best long-term results in terms of pain reduction and maintenance of mobility. Ideally, this should be developed into a form of treatment that is accompanied by physiotherapists and with instructions for independent exercise.

### Example of exercises to stabilize the shoulder blade

- Training of external rotation, passive and against gravity.
- Active training of external rotation against resistance.
- Active training of internal rotation against resistance.

- Training of abduction.
- Active training of shoulder abduction.

These active exercises are also possible in a restricted form for people with short arms.

## 12 Maintaining mobility of the spine from an orthopaedic point of view

Jens Lohmann

### Causes of back pain

Back pain, especially of the lower back, is one of the most common complaints worldwide. In most cases, no specific causes can be found for these complaints. On the other hand, a study [48] from 2015 was able to show that, depending on age, pathological radiological findings were found in a large number of people without any symptoms or complaints being reported. This leads one to the conclusion that a treatment plan should not be made solely on the basis of X-ray.

Estimated incidence of pathological radiological findings of the spine in people without symptoms [48]:

**Table 5: Age-specific prevalence estimates of degenerative spine imaging findings in asymptomatic patients**

Radiological findings	Age in years						
	20	30	40	50	60	70	80
Disc degeneration (intervertebral disc wear)	37 %	52%	68%	80 %	88%	93 %	96%
Disk signal loss (intervertebral disc wear)	17 %	33%	54 %	73%	86%	94%	97%
Disk height loss (height reduction of intervertebral disc)	24 %	34 %	45%	56 %	67%	76 %	84%
Disc bulge (disc protrusion)	30 %	40%	50%	60 %	69%	77%	84%
Disc protrusion	29 %	31%	33%	36%	38 %	40%	43%
Annular fissure (tear of the intervertebral disc)	19%	20%	22 %	23 %	25%	27%	29 %
Facet degeneration (vertebral joint wear)	4 %	9 %	18%	32 %	50%	69%	83%
Spondylolisthesis	3%	5 %	8 %	14%	23 %	35%	50%

It is assumed that back pain has a specific cause only in about 10% to 15% of patients.

### Specific causes of back pain

- Herniated disc
- Narrowing of the spinal canal
- Fractures (vertebral body fractures) due to accidents or osteoporosis
- Tumour diseases
- Infection or inflammation



These diseases are usually serious and can lead to complications involving the nerves and spinal cord within a short period of time. Immediate diagnosis and treatment is, therefore, always required in such cases.

In about 85% to 90% of cases, however, non-specific back pain is present that originates from the interaction of spine with muscle-ligament-apparatus.

#### Non-specific causes of back pain

- Segmental dysfunctions (in manual medicine, blockages temporarily restrict the mobility of one or more joints)
- Disturbed muscle function (muscle shortening, trigger points, linkage)
- Fascia disorders
- Systemic problems (such as coordination disorders, reduced muscular stability or hypermobility).
- Hyperkyphosis of the thoracic spine:
  - Forward head posture, overburdening of the joint surfaces, shortening of the muscle
- → Forward shoulder posture, displacement of the shoulder blade, constriction
- Shoulder joint:
  - Overburdening of the long extensor muscle

#### ***Understanding concept of pain***

A recent study [49] has shown that especially in chronic back pain, extensive training that explains the neurological basics of neck and back pain (pain reduction) has a beneficial effect on the sensation of pain and the function. Patients are informed about the causes of pain and favourable behaviour. The understanding of the fact that pain is not synonymous with tissue damage plays an important role here.

#### ***Practical recommendations for the treatment of chronic back pain***

- Physiotherapy, physiotherapy with equipment, medical training therapy.
- Sensorimotor training.
- Strength training of the global muscles, while taking the muscular imbalances into consideration.

- Segmental stabilisation (motor control deficit according to Richardson) with deconditioning of the deep stabilising musculature (transversus abdominal muscle, multifidus muscle).
- Position-specific training of movement in movement control deficit according to Luomajoki
- Training and treatment of the large body chains (treatment of fascia)  
Prerequisite is free mobility in the fascial system, especially at the transitions between body spaces.
- (Re)learning and practicing natural movement patterns.

### ***Infiltrations and denervation procedures near to the spine***

Invasive procedures may be indicated as an attempt to treat persistent pain that cannot be alleviated by the aforementioned measures. The prerequisite for this is a clear anatomical orientation of pain in the pathological radiological findings.

#### Common invasive therapy methods for the spine

- Facet joint infiltrations
- Sacroiliac joint infiltrations
- Radiofrequency ablation
- Periradicular therapy (PRT)

These procedures should only be used when there is a clear indication and in strict compliance with any contraindications. Ideally, invasive therapies should only be performed in specialised spinal centres.

### ***Recommendation for permanently intractable pain***

If the pain lasts longer than 12 weeks without a specific cause being found, further somatic diagnostics and a comprehensive diagnosis of psychosocial influencing factors should be carried out. This should be done as part of an inter-/multidisciplinary assessment [50].

## 13 List of contributors

### **Klaus Becker**

Office of inclusion Hamburg  
Osterbekstrasse 96  
22083 Hamburg

### **Hendrik Bünzen**

HB-fit  
Haverkamp 10, 24238 Selent

### **Dr. Hilke Weichert**

BG Klinikum Hamburg Rehasentrum City  
Lange Mühren 1, 20095 Hamburg

### **Nina Sörensen**

Peer-to-Peer Beratungsteam des Interessenverband  
Contergangeschädigter NRW e. V.

### **Dr. Alexander Niecke**

Clinic and Polyclinic for Psychosomatic and  
Psychotherapy, University Hospital Cologne (AöR)  
Kerpener Str. 62, 50937 Cologne

### **Dr. Jan-Henrich Stork**

Tabea Hospital, Department of Anaesthesia  
Kösterbergstraße 32, 22587 Hamburg

### **Dagmar Seeger**

Pain Physiotherapy  
University Hospital Göttingen, Clinic for  
Anaesthesiology  
Robert-Koch-Str. 40, 37099 Göttingen

### **Martina Loll**

### **Jenny Schiller**

Physiotherapy Clinic Hoher Meißner  
Hardtstraße 36, 37242 Bad Sooden-Allendorf

### **Sanja Sekulic**

### **Vasilene Matsanova**

Physiotherapy Schön Klinik Hamburg Eilbek  
Dehnhaiide 120, 22081 Hamburg

### **Mathias Prehm**

HumorPille  
Düdelinger Weg 8, 21481 Lauenburg

### **Dr. Michael Plötz**

Bogenstrasse 54b • 20144 Hamburg

### **Annette Jonas**

Practice for Traditional Chinese Medicine  
Beim Grünen Jäger 16, 20359 Hamburg

### **Carsten Schmilgeit**

Faszien-Helden  
Dammtorstraße 27, 20354 Hamburg

### **Dominique Folie**

Motivation - Rehabilitation & Personal Training  
Holstenstraße 184, 22765 Hamburg

### **Dr. Jens Lohmann**

### **Dr. Mathias Weber**

Schön Klinik Hamburg Eilbek  
Dehnhaiide 120, 22081 Hamburg

Greetings from the Hamburg Senate Coordinator for  
Equal Treatment of Disabled People

Importance of exercise for maintaining mobility,  
cardiovascular health and pain prevention

Individual allocation of treatment options as part of a  
lifelong rehabilitation plan

Support in submitting of claims for benefits

A dramatic life. The psychosocial situation of  
thalidomide victims

Pain and movement from the perspective of the pain  
therapist

Pain and movement from the point of view of  
physiotherapy

Round table: Physiotherapists from the Hoher  
Meissner Clinic and the Schön Klinik report on their  
therapy experiences.

Overcoming stress in everyday life, strengthening  
resistance through laughter

Qigong and Taiji - Importance for maintenance of  
health  
Tuina massage

Fascia Therapy

What can a personal trainer do

Maintaining mobility from an orthopaedic point of view:  
Spine

Maintaining mobility from an orthopaedic point of view:  
Shoulder

## 14 References

- 1 *Ferrucci L, Cooper R, Shardell M et al.* Age-Related Change in Mobility: Perspectives From Life Course Epidemiology and Geroscience. *The journals of gerontology. Series A, Biological sciences and medical sciences* 2016; 71(9): 1184–1194
- 2 *Kruse A, Ding-Greiner C, Becker G et al.* Contergan - Endbericht an die Conterganstiftung für behinderte Menschen: Wiederholt durchzuführende Befragungen zu Problemen, speziellen Bedarfen und Versorgungsdefiziten von contergangeschädigten Menschen. *Institut für Gerontologie der Universität Heidelberg* 2012: 1–297
- 3 *Michael J. Sherratt.* Tissue elasticity and the ageing elastic fibre. *AGE* 2009(31): 305–325
- 4 *Patel AV, Bernstein L, Deka A et al.* Leisure time spent sitting in relation to total mortality in a prospective cohort of US adults. *American journal of epidemiology* 2010; 172(4): 419–429
- 5 *Biswas A, Oh PI, Faulkner GE et al.* Sedentary time and its association with risk for disease incidence, mortality, and hospitalization in adults: A systematic review and meta-analysis. *Annals of internal medicine* 2015; 162(2): 123–132
- 6 *Haskell WL, Lee I-M, Pate RR et al.* Physical activity and public health: Updated recommendation for adults from the American College of Sports Medicine and the American Heart Association. *Medicine and science in sports and exercise* 2007; 39(8): 1423–1434
- 7 *Mattson MP, Arumugam TV.* Hallmarks of Brain Aging: Adaptive and Pathological Modification by Metabolic States. *Cell metabolism* 2018; 27(6): 1176–1199
- 8 *Denkinger MD.* Wenn es um Prävention geht, zählt jeder Schritt: Körperliche Aktivität bis ins hohe Alter
- 9 *Leibiger A, Weisser B, Grünhagen M, Köhler M.* Einfluss einer Maßnahme zur betrieblichen Gesundheitsförderung mit Einsatz von Schrittzählern zur Senkung kardiovaskulärer Risikofaktoren (Schrittzählerstudie —DAMP plus 3000!fi)
- 10 *Umpierre D, Ribeiro PAB, Schaun BD, Ribeiro JP.* Volume of supervised exercise training impacts glycaemic control in patients with type 2 diabetes: A systematic review with meta-regression analysis. *Diabetologia* 2013; 56(2): 242–251
- 11 *Steindorf K, Schmidt M, Zimmer P.* Sport und Bewegung mit und nach Krebs – wer profitiert, was ist gesichert? *TumorDiagn u Ther* 2018; 39(05): 301–306
- 12 *Geneen LJ, Moore RA, Clarke C et al.* Physical activity and exercise for chronic pain in adults: An overview of Cochrane Reviews. *The Cochrane database of systematic reviews* 2017; 4: CD011279
- 13 *Mayer F, Scharhag-Rosenberger F, Carlsohn A et al.* The intensity and effects of strength training in the elderly. *Deutsches Arzteblatt international* 2011; 108(21): 359–364

- 14 *Antonovsky A.* Salutogenese: Zur Entmystifizierung der Gesundheit. Tübingen: Dgvt-Verl; 1997
- 15 *Bundeszentrale für gesundheitliche Aufklärung (BZgA), 51109 Köln.* Forschung und Praxis der Gesundheitsförderung - Band 6: Was erhält Menschen gesund?
- 16 *Huber G, Schüle K.* Grundlagen der Sporttherapie: Prävention, ambulante und stationäre Rehabilitation. 2nd ed. München [u.a.]: Elsevier, Urban & Fischer; 2004
- 17 *Kieß E, Hrsg.* Zukunft Personal Training: Erfolg durch Persönlichkeit. [Bergisch-Gladbach]: Premium Personal Trainer Club; 2014
- 18 *Peters KM, Albus C, Lungen M et al.* Gesundheitsschäden, psychosoziale Beeinträchtigungen und Versorgungsbedarf von contergangeschädigten Menschen aus Nordrhein-Westfalen in der Langzeitperspektive: Gutachten im Auftrag des LZG.NRW. Landeszentrum Gesundheit Nordrhein-Westfalen 2014: 1–207
- 19 *Niecke A, Peters K, Samel C et al.* Mental Disorders in People Affected by Thalidomide. *Deutsches Arzteblatt international* 2017; 114(10): 168–174
- 20 *Schleip R.* Lehrbuch Faszien: Grundlagen, Forschung, Behandlung. London: Elsevier Health Sciences Germany; 2014
- 21 *Wilke J, Schleip R, Klingler W, Stecco C.* The Lumbodorsal Fascia as a Potential Source of Low Back Pain: A Narrative Review. *BioMed research international* 2017; 2017: 5349620
- 22 *Yahia L, Rhalmi S, Newman N, Isler M.* Sensory innervation of human thoracolumbar fascia. An immunohistochemical study. *Acta orthopaedica Scandinavica* 1992; 63(2): 195–197
- 23 *Benjamin M.* The fascia of the limbs and back--a review. *Journal of anatomy* 2009; 214(1): 1–18
- 24 *Willard FH, Vleeming A, Schuenke MD et al.* The thoracolumbar fascia: Anatomy, function and clinical considerations. *Journal of anatomy* 2012; 221(6): 507–536
- 25 *Maslow AH.* Motivation and personality; 1954
- 26 *Maslow AH.* Motivation und Persönlichkeit. 15th ed. Reinbek bei Hamburg: Rowohlt; 2018
- 27 *Chenot J-F, Greitemann B, Kladny B et al.* Non-Specific Low Back Pain. *Deutsches Arzteblatt international* 2017; 114(51-52): 883–890
- 28 *Freyenhagen R, Baron R, Gockel U, Tölle TR.* painDETECT: A new screening questionnaire to identify neuropathic components in patients with back pain. *Current medical research and opinion* 2006; 22(10): 1911–1920
- 29 *Mense S.* Muscle pain: Mechanisms and clinical significance. *Deutsches Arzteblatt international* 2008; 105(12): 214–219
- 30 *Nicotra A, Newman C, Johnson M et al.* Peripheral Nerve Dysfunction in Middle-Aged Subjects Born with Thalidomide Embryopathy. *PloS one* 2016; 11(4): e0152902
- 31 *Häuser W, Bock F, Engeser P et al.* Long-term opioid use in non-cancer pain. *Deutsches Arzteblatt international* 2014; 111(43): 732–740

- 32 *Teske J, Weller J-P, Larsch K et al.* Fatal outcome in a child after ingestion of a transdermal fentanyl patch. *International journal of legal medicine* 2007; 121(2): 147–151
- 33 *Binder A, Baron R.* The Pharmacological Therapy of Chronic Neuropathic Pain. *Deutsches Arzteblatt international* 2016; 113(37): 616–625
- 34 *Gerd Glaeske KS.* Cannabis-Report; 2018
- 35 *Allan GM, Ramji J, Perry D et al.* Simplified guideline for prescribing medical cannabinoids in primary care. *Canadian Family Physician* 2018; 64(2): 111–120
- 36 *Staal JB, Bie RA de, Vet HCW de et al.* Injection therapy for subacute and chronic low back pain: An updated Cochrane review. *Spine* 2009; 34(1): 49–59
- 37 *Carette S, Marcoux S, Truchon R et al.* A controlled trial of corticosteroid injections into facet joints for chronic low back pain. *The New England journal of medicine* 1991; 325(14): 1002–1007
- 38 *Niemier K.* Langzeiteffekte interventioneller Behandlungen von chronischen Schmerzen des Bewegungssystems. Retrospektive Verlaufsstudie wiederholter stationärer Behandlungen. *Schmerz (Berlin, Germany)* 2012; 26(2): 185–191
- 39 *Gerbershagen HJ.* Chronifizierungsrisiken. In: *Schmerzmedizin 1000 Fragen*. Stuttgart [u.a.]: Thieme; 2012: 201–206
- 40 *B. Kröner-Herwig et al., Hrsg.* Schmerzpsychotherapie: Mainzer Stadienmodell der Schmerzchronifizierung (MPSS). Berlin Heidelberg: Springer Verlag; 2017
- 41 *Burtscher A, Breunig I, Goetz M et al.* Multimodale Schmerztherapie für die Behandlung chronischer Schmerzen. *Nervenheilkunde* 2018; 36(05): 361–368
- 42 *Benz C, Bull T, Mittelmark M, Vaandrager L.* Culture in salutogenesis: The scholarship of Aaron Antonovsky. *Global health promotion* 2014; 21(4): 16–23
- 43 *Moffett JK, Mannion AF.* What is the value of physical therapies for back pain? Best practice & research. *Clinical rheumatology* 2005; 19(4): 623–638
- 44 *Flor H.* New developments in the understanding and management of persistent pain. *Current opinion in psychiatry* 2012; 25(2): 109–113
- 45 *Lindström I, Ohlund C, Eek C et al.* The effect of graded activity on patients with subacute low back pain: A randomized prospective clinical study with an operant-conditioning behavioral approach. *Physical therapy* 1992; 72(4): 279-90; discussion 291-3
- 46 *Mlinac ME, Feng MC.* Assessment of Activities of Daily Living, Self-Care, and Independence. *Archives of clinical neuropsychology the official journal of the National Academy of Neuropsychologists* 2016; 31(6): 506–516
- 47 *Arnold B, Brinkschmidt T, Casser H-R et al.* Multimodale Schmerztherapie für die Behandlung chronischer Schmerzsyndrome. Ein Konsensuspapier der Ad-hoc-Kommission Multimodale interdisziplinäre Schmerztherapie der Deutschen Schmerzgesellschaft zu den Behandlungsinhalten. *Schmerz (Berlin, Germany)* 2014; 28(5): 459–472
- 48 *Brinjikji W, Luetmer PH, Comstock B et al.* Systematic literature review of imaging features of spinal degeneration in asymptomatic populations. *AJNR. American journal of neuroradiology* 2015; 36(4): 811–816

- 49 *Malfliet A, Kregel J, Coppieters I et al.* Effect of Pain Neuroscience Education Combined With Cognition-Targeted Motor Control Training on Chronic Spinal Pain: A Randomized Clinical Trial. *JAMA neurology* 2018; 75(7): 808–817
- 50 *Bundesärztekammer (BÄK), Kassenärztliche Bundesvereinigung (KBV), Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (AWMF).* Nationale VersorgungsLeitlinie Nicht-spezifischer Kreuzschmerz – Langfassung, 2. Auflage. Version 1



*"Help! Between hospital and recovery. With a lot of empathy, we support projects and actions that are not always possible to implement in hospitals - but are necessary for recovery."*

## Get involved!

Support us in promoting health in a better way.

The goal of SchönHelfen, der Schön Klinik Stiftung für Gesundheit gGmbH, is - according to the articles of association - to promote public health, science and research, education and training, sport and to assist the people in need in a charitable way.

Donations are welcome!

**Bank details: Deutsche Bank - IBAN DE81 7007 0010 0192 3705 00**



CONTERGAN  
SPRECHSTUNDE  
HAMBURG

Schön Klinik Stiftung  
für Gesundheit