Lipedema

A Practical Guidebook

Zaher Jandali
Lucian P. Jiga
Corrado Campisi
Editors

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Preface

Many women suffer from a painful disproportional tissue distribution in the extremities, especially the legs, and often know that something is wrong with them long before being diagnosed. It is the pain in the legs and arms that leads those affected to embark on a sometimes adventurous search for a diagnosis and possible ways for medical treatment. Lipedema is often misdiagnosed, so usually patients will have to change several doctors before finally confronted with the real diagnosis. As a rule, the first question most of the patients ask after being diagnosed is how the treatment looks like and how long will it take. Ignorance about the condition often fuels fears that the condition will progress rapidly without being able to do anything to stop it. These in turn will have an important negative effect on the patient's well-being but also generate a major psychological burden affecting the self-esteem and social relations. Aesthetics also play an important role that should not be underestimated.

Although knowledge about the disease "lipedema" has improved significantly in recent years, especially since entire health systems have considered giving it more attention, it is often based on incorrect information, assumptions, and facts. One thing is certain: there is a general lack of information on the subject of lipedema. This starts with the scientific side, continues with the specialized knowledge, and ends with the treatment, whether conservative or surgical. Therefore, it is important to us that we approach the topic of "lipedema" systematically and illuminate it from all aspects.

We hope, through this book, to offer at least a small contribution towards a much better understanding of this complex disease. Irrespective of this, professional societies, physicians, and centers must continue to work on transparency and knowledge transfer on all fronts in the future. Only in this way can we come closer to the goal of providing the best possible care for those affected.

With this book, we would like to provide those affected by lipedema with a practical guide.

We wish you an informative read.

Niedersachsen, Germany — Zaher Jandali
Niedersachsen, Germany — Lucian Jiga
Genova, Italy — Corrado Campisi

The Rationale for the Book

The idea for the book had been floating around in our minds for a long time, but as is often the case, there is simply not enough time to implement such projects.

The idea finally took form during one of the yearly meetings we organized for our colleagues for education and training in the field of lymphatic and lipedema surgery. I remember well when we talked about the poor transfer of knowledge to those affected. It doesn't even start with the patients; it starts with us, the physicians! There are many colleagues who have never heard of lipedema or lymphedema and are not familiar with the differentiation between these two conditions. What level of knowledge should the patients have about this disease?

At the same time, talking about our scientific projects we found out that we do a lot in the field of lymphatic surgery, but quite little to nothing in the field of lipedema, although this issue accounts for a much larger share in our clinical routine. Furthermore, contemplating the actual evidence on lipedema we identified a major gap in both medical and patient-oriented literature.

Our motivation for this book was to convey the current state of scientific knowledge in terms understandable for our patients and everyone interested to learn more about this condition.

Acknowledgements

Most readers see the editors and authors as the creators of a book. As this might be true for the idea and content, completing such a task takes much more than these to achieve. As such, we would like to thank all who helped and supported us from the bottom of our hearts starting with our patients who offered us their unbounded trust, motivating us to write this book. For us, it is a matter of the heart to help patients affected with lipedema.

We would like to thank Mrs. Jandali and Mr. Stober (www.svenstober.com) for the great pictures, with the help of which readers will definitely get a much better view of the individual explanations throughout the book.

We owe a big thank you to Springer, who believed in our idea and recognized the need for this book. Special mention should be made of the project planner Ms. Kraplow and project manager Ms. Beisel. We have rarely experienced such dedicated cooperation.

Very special thanks go to our proofreader Mrs. Thürk. From the first moment of cooperation, we felt very well taken care of. The proofreading made the book an easy lecture, giving it a great boost. Thank you for your patience with us. It was certainly a difficult task, which you mastered brilliantly.

About this Book

The idea to write this book was fueled from many years of experience in dealing with affected patients and their families. With this book, we have set ourselves the goal of giving the reader an in-depth overview on all aspects related to "lipedema" helping you to make your own treatment decisions.

At the beginning of the book, the current scientific knowledge is summarized. In doing so, we dispel many half-truths and myths. In a structured way, the cause of lipedema, its clinical picture, and how this disease manifests itself are explained. Finally, its consequences as well as supposedly similar diseases such as pure lymphedema and obesity are discussed. Furthermore, we discuss the current classification we use of lipedema as we would like it to be.

We then enter into our actual core topic, the treatment of lipedema. In addition to the aspects of the timing of a treatment, we deal with the different conservative and surgical options. At the end, we provide the reader with our recommendations for treatment.

All the above are of course only rough headings of the topics that await you in this book. Look forward to exciting details and in-depth expertise to help you sharpen your view on the topic of "lipedema."

After reading this book you will be familiar with all actual treatment options for lipedema. In particular, through the information you will discover in this book, you will be given the chance to weigh up the advantages and disadvantages of each individual procedure according to your own symptoms. We are confident that by reading this guide, your level of knowledge and your self-confidence will increase, making the next visit to your doctor a "walk in the park" instead of a chaotic uncontrolled input of unknown information.

However, this book is neither thought as a substitute for a doctor appointment and since medicine is in a constant state of development nor as a complete or up to date reference for lipedema. Likewise, each chapter reflects the opinion of its respective authors.

This book is NOT a scientific publication. It targets mainly the "non-medical readership," who by reading it should gain a thorough understanding of this painful fat tissue disease.

No before-and-after pictures of operations are shown in this book, so as not to give the impression that advertising for surgical measures is being carried out. If before-and-after images are shown, they are 3D illustrations and not actual images.

Enjoy reading.

Contents

About the Authors

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Zaher Jandali, M.D. graduated in 2006 at the University Medical Center Hamburg-Eppendorf (UKE) in Hamburg as medical doctor. In 2012 he completed his training as consultant in plastic and aesthetic surgery in the Department of Plastic, Aesthetic, Reconstructive and Hand Surgery at the Asklepios Clinic in Hamburg-Wandsbek. Since day one, Dr. Jandali has been intensively involved with the topic of "lipedema." Early on, he began giving lectures to those affected and interested, as well as to patient support groups. This was followed by lectures on this topic at national and international congresses. Since 2016, Dr. Jandali occupies the chair position of the Clinic for Plastic, Reconstructive, Aesthetic and Hand Surgery at the Evangelical Hospital in Oldenburg (Lower Saxony). Dr. Jandali further developed several surgical techniques for lipedema, combining different approaches to achieve better and safer results. Since 2007, his main focus has been on the treatment of lipedema and lymphedema. He performs liposuction using a unique technique optimized for lipedema. Dr. Jandali also focuses on reconstructive surgery after weight loss, as well as aesthetic and reconstructive microsurgery. Dr. Jandali is a member of the following professional societies: DGPRÄC, German Society of Plastic, Reconstructive and Aesthetic Surgeons DGH, German Society for Hand Surgery WSRM, World Society of Reconstructive Microsurgery www.jandali.de www.lipold.de

Lucian Jiga, M.D. completed his medical studies at the Victor Babes University of Medicine and Pharmacy Timisoara in Romania. In 2002, he moved to the Ruprecht-Karls-University of Heidelberg for pursuing a research fellowship that led him to successfully defend his doctoral thesis three years later. After his stay in Heidelberg, in 2005 Dr. Jiga moved back to Timisoara to the University Clinic for Vascular Surgery and Reconstructive Microsurgery. Starting in 2009, he occupied the section chair position as Associate Professor in the Department of Reconstructive Microsurgery. In 2013, Dr. Jiga returned to Germany as a senior consultant of the Clinic for Plastic, Aesthetic, Reconstructive and Hand Surgery at the Evangelisches Krankenhaus in Oldenburg. Since 2016 he shares here the chair of department position with Dr. Jandali. Dr. Jiga looks back on a large number of international lectures and scientific publications. In addition to the treatment of lipedema, his clinical work focuses on reconstructive surgery after breast cancer and after weight loss, the treatment of lymphedema, microsurgical reconstructive surgery, especially to preserve extremities, and complex hand surgery. Dr. Jiga is a member of the following professional societies: DGPRÄC, German Society of Plastic, Reconstructive and Aesthetic Surgeons DGH, German Society for Hand Surgery WSRM, World Society of Reconstructive Microsurgery TTS, The Transplantation Society.

Benedikt Merwart completed his medical studies at Heinrich Heine University in Düsseldorf, Germany, graduating in 2015. He discovered his interest in the treatment and therapy of lipedema and lymphedema early on in his training, which he began in 2015 at the Clinic for Plastic, Aesthetic, Reconstructive and Hand Surgery at the Evangelisches Krankenhaus under the direction of Dr. med. Z. Jandali and Dr. med. L.P. Jiga. Mr. Merwart regularly lectures on this topic for affected individuals and self-help groups as well as at national and international professional congresses. His other areas of interest include breast reconstruction after breast cancer treatment and restoration of body shape after massive weight loss. Mr. Merwart is the author of several scientific publications and books.

Ralf Weise, M.D. is a specialist in general, visceral and special visceral surgery, a specialist in surgical proctology, certified in minimally invasive surgery (CAMIC), and a specialist in nutritional medicine. Since 2006, he has been the head physician of the Clinic for General and Visceral Surgery at St.-Marien-Hospital in Friesoythe. In 2007, he founded the North-West Obesity Center, which was certified as a Center of Excellence in 2011 and as a Reference Center in 2015. In 2017, the Obesity Center celebrated its 10th anniversary. To date, more than 3,500 obese patients have been treated in Friesoythe and more than 1,700 metabolic interventions have been performed. Dr. Weise has served as medical director at St.-Marien-Hospital in Friesoythe since 2013. He has given numerous lectures and presentations at international congresses and has published articles on obesity in four books. www.weiseoperiert.de www.adipositas-zentrum-nord-west.de

The Lipedema

1

Zaher Jandali, Benedikt Merwart, and Lucian Jiga

1.1 Introduction

Lipedema is recognized as a disease, yet it is trivialized by many colleagues, frequently being used as a "way out diagnosis," according to the motto: "If we don't find anything and you have thick legs, then you have lipedema." Patients with lipedema suffer from a serious illness that is responsible for significant suffering. The complex clinical picture of lipedema cannot simply be reduced to painful legs and arms. It cannot be equated with "thick legs" or "thick arms," nor can all thick legs and arms be attributed to lipedema. It is therefore important to make an accurate diagnosis clearly distinguishing lipedema from other diseases (Fig. 1.1).

Perhaps you are a patient yourself, with high hopes of being cured, reading this book to learn more about your disease. If so, you match the profile of the majority of patients addressing us for possible treatment. Unfortunately, after their first appointment, most of these patients are faced with the fact that such expectations are sometimes far from what is actually possible. Either social media or physicians often fuel such discrepancies. Particularly inexperienced colleagues allow themselves, as a display of unsustainable knowledge "in front of the camera," to bring the topic "lipedema" into the public eye with questionable advances just for the sake of media attention. Despite several existing claims on lipedema being a curable disease, there is, unfortunately, no cure for it to date. However, with the right measures, the suffering can be sustainably alleviated and quality of life restored.

We have deliberately chosen these provocative introductory words to draw attention to the lack of acceptance of "lipedema" as a disease. If you really want to understand lipedema, you first have to find out the state of knowledge about this disease. Thus, we would first briefly discuss the history and origin of the term "lipedema."

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Fig. 1.1 Typical clinical picture of moderately pronounced lipedema

The Term "Lipedema"

The term "lipedema" comes from the ancient Greek term "fat swelling." It is composed of the two words λίπος, lípos, "fat" and the word οἴδημα, oídēma, "swelling." Synonyms for the term lipedema include pillar leg, lipalgia, adipoalgia, lipo-fat disease, lipohypertrophia dolorosa, and adiposity dolorosa of the arms and legs. In addition to these synonyms, there are many other terms of the same category that should NOT be used either because having a different meaning or no meaning at all. The examples are lipohypertrophy, breeches syndrome, lipidosis, fat-leg syndrome, lipdem, fatty leg, hyperplasia dolorosa, lipohyperplasia dolorosa, zonal obesity, and others (Table 1.1). Several of these terms will be explained in the book, as they are directly related to lipedema or should be distinguished from it.

Table 1.1 Actual and apparent synonyms of lipedema

Actual synonym	Apparent synonym
Painful column leg	Fat leg
Lipalgia	Lipdema, lipidosis
Adipoalgia, Adipoalgesia	Fat-leg syndrome
Lipohypertrophia dolorosa	Lipohypertrophy
Obesity dolorosa	Lipohyperplasia dolorosa
Painful lipedema syndrome	Hyperplasia dolorosa
Adiposis dolorosa	Zonal obesity

▶ We have long advocated abandoning the term lipedema and using the simple umbrella term "adipose tissue disease" with the sub-terms "lipalgia" or the term we introduced, "lipodolorosa (chronica)."

History of the Disease

Let us first look back at the history of the disease "lipedema" and what we have learned from the past. The first ones to describe lipedema were the physicians E.V. Allen and E.H. Hines in 1940 publishing the first scientific texts on the subject of "lipedema" in 1940, 1951, and 1952. Many scientific papers, websites and colleagues still refer to the rather old first descriptions. We roughly summarize the studies below to reflect their core statements.

The first of the three publications from 1940 is entitled "Lipedema of the legs: a syndrome characterized by fat legs and orthostatic edema" and describes a clinical syndrome that is often very distressing for those affected and could only be observed in women. Accordingly, the main complaints were swelling and an increase in adipose tissue volume and water retention in the area of the buttocks and legs. The swelling below the knee joint occurs predominantly when one is on one's feet a lot or during warm weather. Pain in the legs is also common. Furthermore, the syndrome is associated with a gradual increase in body weight. Unlike obesity, in which food intake exceeds the body's caloric needs, the increase in subcutaneous fat only on the buttocks and legs is not easily explained. The edema of the affected persons results from a passage of fluid from the blood into the tissue. If there was a fat distribution disorder in favor of the lower extremities without obesity, dietary measures would have no chance of success.

The second publication from 1951 with the very similar title "Lipedema of the legs; a syndrome characterized by fat legs and edema" describes lipedema as a progressive disease with orthostatic swelling of the legs. Compared to lymphedema, a decrease in leg swelling will not be facilitated by lying down. In this observational study,119 lipedema patients were presented, the observations from the first publication from 1940 being confirmed.

Only 1 year later, Hines published another article on lipedema with the title "Lipedema and physiologic edema." Here, he continues to speak of adipose tissue proliferation and water accumulation in lipedema. What was new was the exclusion of the feet region in the description of fatty deposits or edema. The absence of edema in the feet was explained by tight-fitting shoes that could have prevented it.

These three studies were therefore the "birth" of lipedema as a disease and are still quoted today. Many of the facts described here have retained their validity, but there are also some aspects that we now see differently. One example of this is the term "progressive" disease, which we discuss in more detail in Sect. 1.5.

- Cited facts about lipedema often come from rather older studies and do not meet current scientific standards.

Let's get to one of the biggest misconceptions about lipedema:
"Lipedema is a condition associated with lymphedema."

This statement is wrong and has been outdated for a long time. Regrettably, however, this has yet to be understood by those affected, by the press and a significant number of scientific papers.

Rare cases in which there a combination of lipedema and lymphedema can be diagnosed clinically make the exception to this claim. Moreover, the outdated disease name suggests that it is edema, which in the true sense, it is not but rather pathologically distributed fat tissue.

- The first three publications on lipedema are:
- Allen EV, Hines EA (1940) Lipedema of the legs: a syndrome characterized by fat legs and orthostatic edema. Proc Staff Meet Mayo Clin. 15: 184–187.
- Wold LE, Hines EA Jr., Allen EV (1951) Lipedema of the legs; a syndrome characterized by fat legs and edema. Ann Intern Med 34(5): 1243–1250.
- Hines EA Jr. (1952) Lipedema and "Physiologic" Edema. Proc Staff Meet Mayo Clin 27(1): 7–9.
- Lipedema is a real disease that must be taken seriously.

1.2 Causes and Emergence

In this section, among other things, we want to go on causal research and talk about the pathophysiology of lipedema. We will not only discuss our own knowledge but also go into those facts that are unfortunately far too often sold as truths. You can expect an exciting potpourri of scientifically proven facts, hypotheses, suppositions, half-truths as well as insights gained from observations.

The term "pathophysiology" is composed of two terms. The word "pathology" comes from the ancient Greek πάθος, páthos, meaning "disease," and λόγος, lógos, the doctrine. Pathology, then, means the doctrine of disease, the "doctrine of afflictions." The word physiology is also composed of two words and comes from the ancient Greek: φύσις, phýsis, 'nature' and λόγος, lógos, 'doctrine'. Physiology is consequently the study of what is normal or healthy. Pathophysiology thus describes

which functional mechanisms lead to pathological changes and how the sick body functions.

Before we turn to the pathophysiology, we must briefly discuss the disease triggering factors. To date, the trigger mechanism for a fat distribution disorder is unknown. Also, why lipohypertrophy that it can be an inherited condition (the literature speaks of an accumulation of up to 60% in first-degree relatives). In addition, there are factors such as hormonal balance and lifestyle. But one thing is certain: lipedema takes place in or around the adipose tissue. That is why we are taking a closer look at the adipose tissue.

- Triggers of lipohypertrophy and lipedema are unknown.

1.2.1 Adipose Tissue

When talking about adipose tissue, we distinguish between "storage fat" and "constitutional" fat. We find the constitutional fat mainly in the area of organs such as the kidney, but also in our extremities, such as the hands and feet. In the area of the heel, it serves, among other things, to absorb shocks when walking, thus the fat having here a purely mechanical function. The storage fat is the classic subcutaneous adipose tissue, which acts as an energy storage reserve and "cold insulation" or insulator.

Types

We distinguish a total of three types of adipose tissue: white, beige, and brown adipose tissue (Fig. 1.2). In the context of lipedema, only the white adipose tissue, which has the function of storage or depot fat, is of interest to us.

However, before we take a closer look at white adipose tissue, for the sake of completeness we will briefly discuss the other two forms.

Until 2009, it was assumed that brown adipose tissue was only present in babies. However, a study showed that adults also have a proportion—albeit very small—of brown fat. Brown fat has the property that it can generate heat. This occurs in the so-called mitochondria, which work like small power plants within the cells. This

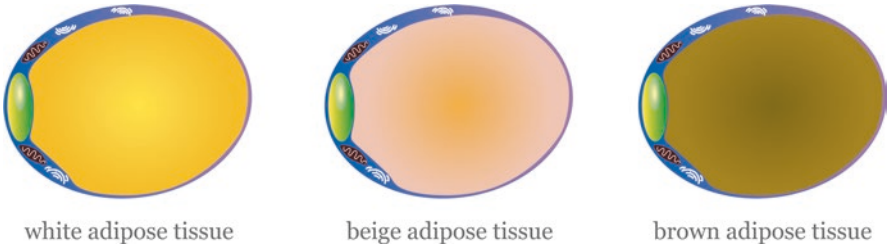

Fig. 1.2 White, beige, and brown adipose tissue

form of adipose tissue is very common in the animal kingdom, especially in animals that hibernate so it will help them to quickly raise their body temperature as soon as they wake up. Adults, on the other hand, have only limited brown fat depots.

Beige adipose tissue is found sporadically between the white adipose tissue. The function is not conclusively clarified; however, heat production is also discussed.

Let us now turn to the white adipose tissue. We find this as subcutaneous adipose tissue all over the body and thus also in the regions where lipedema takes place.

The subcutaneous fat tissue, where lipedema takes place, consists of white adipose tissue.

Adipose tissue is a form of connective tissue and consists, among other things, of fat cells, the so-called adipocytes. One can imagine adipose tissue as a sponge in which the "holes" are filled with adipocytes. The adipocytes are surrounded by many other different cells, scaffolding fibers and blood vessels and are combined within the surrounding tissue into small conglomerates, so-called lobules. Also located in the adipocyte environment are the progenitor cells of the adult adipocyte, which we will look at in more detail later in this section.

Depending on the body region, the subcutaneous fat tissue is structured differently. The total layer of subcutaneous fat tissue is divided into two compartments by a fat fascia (connective tissue plate): superficial and deep. The superficial compartment contains predominantly finer fat cells, while the deep compartment contains larger fat cells or fat conglomerates, each in proportion to the respective region. This means that, for example, the conglomerates of the deep fat layer on the buttocks are much larger than those on the forearm. In Fig. 1.3, we see an example of such a structure.

The white adipose tissue has different functions. In addition to its function as a metabolic organ, it mainly acts as a storage or depot fat. In addition, it can act as insulating fat to protect against heat loss and as a buffer zone as well as a protective layer in the form of building fat (kidney-bearing fat, sole of foot, eye).

► The largest proportion of white adipose tissue is found in the subcutaneous adipose tissue.

Structure and Function

Similar to the way human skin acts as a barrier to the environment, a fat cell (adipocyte) is separated from the environment by a cell membrane (cell wall).

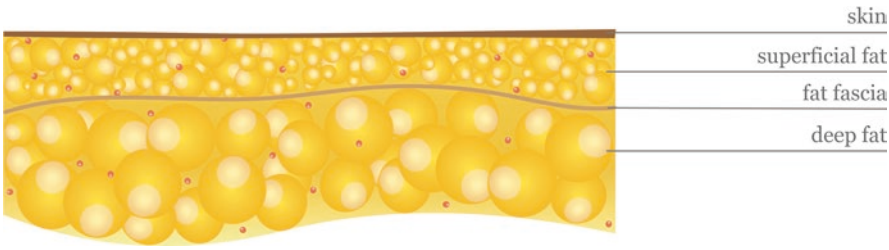

Fig. 1.3 Adipose tissue buildup in the subcutaneous fat tissue

This cell wall contains a number of different interfaces to which messenger substances can dock and trigger cell actions. We call these interface receptors. Examples are estrogen, insulin, and adrenaline receptors. In lipedema, receptors seem to play a central role. Therefore, we will go into this topic again in more detail in Sect. 1.2.3.

The fat cell, like any cell, has a "basic equipment," that is, a typical cell structure with a nucleus, where the genetic information (DNA) is located, with its energy providing mitochondrial apparatus and so on. Within the fat cell are the cell organelles, surrounded by the cytoplasm with the basic water-based structure of the cell, the cytosol. These are responsible for different functions of the cell.

The special feature of each white fat cell is its function of storing fat. The fat inside the cell is not limited by any wall or similar. The so-called lipid droplet (the fat content in the fat cell) is delimited in the cell only by a light-colored fringe (delimiting vimentin filaments) visible under the microscope. Depending on whether one or more fat droplets are found in the fat cell, we distinguish univacuolar (one fat droplet) from multivacuolar fat (several fat droplets) whereas white adipose tissue is predominantly univacuolar fat.

In Fig. 1.4 we show an example of a univacuolar fat cell with a typical, voluminous lipid droplet accounting for about 95% of the cell volume, pushing the nucleus to the cell membrane forming a so-called signet ring structure of the cell nucleus.

The energy balance of our body is subject to a constant dynamic. We distinguish between an anabolic and a catabolic phase. During the anabolic phase, the body's own energy storage components are built up under a certain energy consumption. For fat cells, this means that the lipid droplet is built up as a fat store in an anabolic phase and broken down accordingly in a catabolic phase.

A buildup and storage of fatty acids in a fat cell is only possible when there is an energetic surplus. The storage of energy in fat form is only possible through two mechanisms:

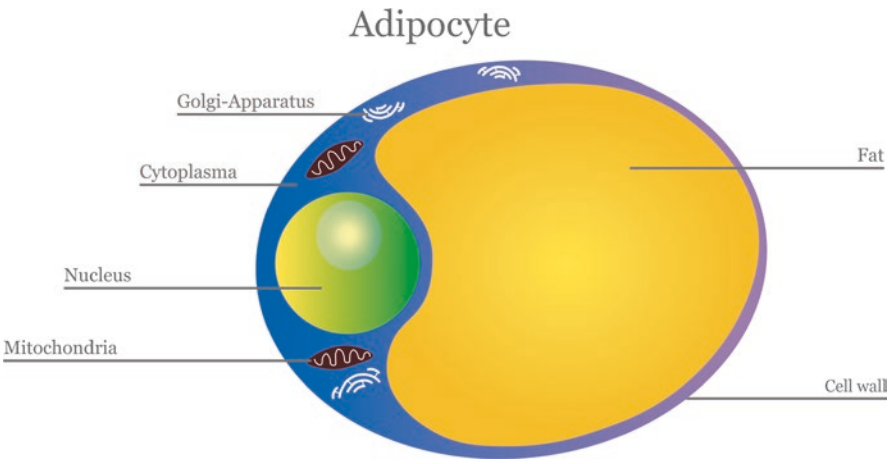

Fig. 1.4 Univacular fat cell with typical giant lipid droplet

1. absorption and storage of fats via food intake or,
2. body's own production of fatty acids, for example, by carbohydrates, a process is also known as fatty acid synthesis.

The breakdown of fatty acids and the resulting energy is referred to as lipolysis. The buildup and breakdown of fat are hormonally controlled, the hormones insulin and adrenaline play being the key players in this process.

Did you know that a fat cell has a limited lifespan and is subject to a life cycle? Fat cells are continuously built up and broken down by the body. An adult adipocyte grows from a fat precursor cell, a so-called preadipocyte, which in turn grows from a connective tissue precursor cell. You are probably wondering now how a fat cell knows that it is to become a fat cell? For the differentiation or development of such a fat cell, several intricate messenger compounds and processes are required. Explained simply, there is something like a program that is played leading to the production of all the necessary messengers so that the precursor cells understand that they need to turn into a fat cell. When the life of the fat cell is over, it dies and is degraded. A new fat cell develops in its place (Fig. 1.5).

If we take another look at the structure of adipose tissue, we have to imagine a convolute of fat cells, blood vessels, and other connective tissue cells. The so-called precursor cells (stem cells) are attached to the small blood vessels, from which new, young fat cells can develop by means of appropriate signals. In the process, they take up appropriate triglycerides (fatty acids) from the blood, through which they build up your fat droplet.

Body fat tissue can expand from 2–3% to over 60–70% of the body volume. A normal weight man has a fat tissue percentage of about 10–20%, a woman about 15–25%.

In childhood and adolescence, there is an increase in the absolute number of fat cells, but in adulthood, their numbers remain under physiological conditions

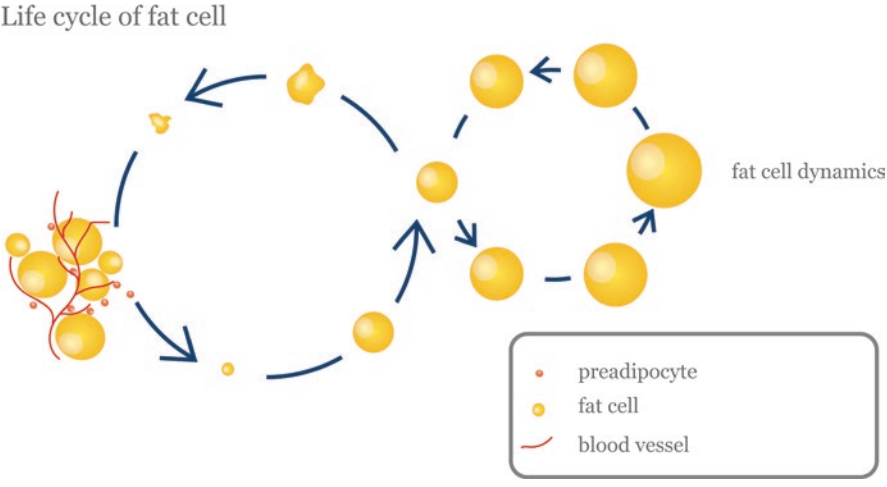

Fig. 1.5 The picture shows the theoretical life cycle of a fat cell