Cosmetic Stature Lengthening Frequently Asked Questions (FAQ's)

Dr. Dror Paley,
Director Paley Advanced Limb Lengthening Institute,
West Palm Beach, Florida.
dpaley@lengthening.us

For further inquiries contact our patient co-ordinator:
Caroline Eaton  ceaton@lengthening.us  (561-307-8703)

For administrative or financial inquiries please contact the Institute Administrator
Ali Birjandi  abirjandi@lengthening.us  (561-310-8076)

Frequently Asked Questions (FAQ’s) (bold letters)

Who requests this operation?

The majority of people who seek this surgery are unhappy with their body image. Body image is the way we perceive ourselves. As it relates to height it is the way we perceive our own height and our body proportions (limb length relative to trunk length).

Is there a name for this condition?

The psychologist that I worked with for over 20 years and who evaluated almost all of my patients with this condition between 1988 and 2008, Dr. Walter Windisch, called this condition Height Dysphoria (Dysphoria literally means unhappy, the opposite of euphoria). In other words unhappy with your height. Another term that has been used is one I coined; Height Neurosis.

There is also a rarer version of Height Dysphoria, which is body dysmorphic disorder. This is not a neurosis but is actually a psychosis. It is very important to differentiate the two. The latter should not be treated with surgery.

What is the normal range of adult height in the population?
When assessing distribution of height in the population, we consider the normal bell curve. We divide people by distribution around the mean (average). Normal height is considered \( \pm 3 \) standard deviations (SD) from the mean. Stature below 3 SD from the mean in persons without a medical condition such as dwarfism or growth hormone deficiency is considered constitutional short stature. A physician defines the normal range of height between the 5th and 95th percentiles. The lower limit of so-called normal stature for men is 5'5" (166 cm) and for women is 5'0" (153 cm).

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**What is the relationship of height to Height Dysphoria**

While a person’s actual height is related to the condition there is no height threshold under which you cannot suffer from height dysphoria. Most of us would assume that you could only suffer from Height Dysphoria if you are ‘short’. The problem is that the perception of who is short varies from person to person. That threshold differs along racial, national and cultural lines: 5’10” is tall in India but short in Holland.

The following anecdote illustrate the point: A man flew all the way from Holland to see me regarding stature lengthening. He was 5’11” tall. He said that since he was a teenager he has suffered from feeling short. He is the shortest male in his family and even his sister is his height. All of his friends are much taller. He reminded me that the Dutch are the tallest people in the world. He is the same height as me. I have never perceived myself as short nor have any of my family or friends. I therefore had difficulty considering him for stature lengthening. I sent him for psychologic evaluation. The psychologist report showed he suffered from the same body image
problem as all of the other patients we had evaluated. Despite his seemingly tall height he suffered from Height Dysphoria.

When we studied the relationship of starting height to the diagnosis of Height Dysphoria we found that patients starting height varied from 4’10” to 5’11” for males and 4’6” to 5’8” for women. While more of the patients were at the lower end of this spectrum, the fact that some were at the upper end clearly demonstrated that height is not the primary problem. The primary problem is the psyche’s perception of height and proportion.

**Is there a height threshold above which stature lengthening is not appropriate?**

Based on the above findings the answer should be no. I have learned to remove my personal bias regarding height from the evaluation. It is the patients perception that counts. As regards risks of the procedure they are no greater if you are taller. In fact they should theoretically be less since the percent increase in length of a longer bone is less.

**What are the methods available to do stature lengthening?**

There are three methods:

1) External fixation (EF) only
2) LON or LATN
3) Implantable limb lengthening (ILL)

What are the pros and cons of each method

External Fixation only pros

- Least expensive since implants can be reused
- Least invasive
- Can do both femurs and both tibias at the same time (usually 5cms femurs and 5cms tibias; total 10cms)
- More expensive then EF but less expensive than ILL
- Allow weightbearing (WB) for transfers during distraction; WB as tolerated (WBAT) during consolidation

External fixation only cons

- Pins come out through skin
- Pin infections
- More pain
- More scars
- Longer recovery time
- Risk of fracture

LON or LATN is a way to shorten the external fixation treatment time by using an internal rod in the bone to support the bone after the lengthening is completed permitting early removal of the EF.

LON/LATN pros

- Shorter EF treatment time
- Minimal risk of fracture
- Shorter recovery than EF only
- Allow weightbearing (WB) for transfers during distraction; WB as tolerated (WBAT) during consolidation

LON/LATN cons

- Pin infections
- Pin site scars
- Can only do two bones at one time (femurs or tibias) (maximum lengthening is 7.5cms)

Implantable Limb Lengthening pros

- No pins or pin infections
- Less pain
- Better joint range of motion
- Faster rehabilitation
- Faster bone consolidation
- Faster full weightbearing without external aids or device
- Less scarring
- Allow weightbearing (WB) for transfers during distraction and for one month of consolidation; (WBAT) after one cortex of bone union seen

Implantable Limb Lengthening cons

- Can only lengthen two bones (two femurs or two tibias) with one surgery
- Can lengthen up to 7.5cms depending on the device
- More invasive than EF alone. Less invasive than LON/LATN
- Most expensive since implants are more expensive and cannot be reused.
The most appealing of these is ILL since the incisions and scars are minimal. There is no external device. There are no pins going through the skin and muscle and therefore no risk of pin infection. There is less pain involved. ILL is the most cosmetic of the cosmetic LL procedures.

**What can I do to prepare for surgery?**

**Education:** Read all printed materials we provide. Book a consultation and come with your questions written down so you can get the answers you need. Email us any additional questions you may think of later.

**Physical preparation:**

Stretching exercises may help. For femur lengthening the important stretching is of the: 1) quadriceps and especially the rectus femoris muscle (bend knee with straightening of hip at same time. Can be done standing pulling foot behind butt and leaning back or kneeling with leaning back); hamstrings(knee straightening while flexing hip); and fascia lata (cross legged stretches with hip straight). For tibial lengthening the only important stretches are for the heel cord (maximum dorsiflexion (foot up) with full knee extension.

Stop smoking and exposure to second hand smoke.

Stop all anti-inflammatory meds.

**Fiscal/Organization preparation:**

Organize your life so you can put it on hold for at least three months. You will need to stay in West Palm Beach for at least 9 weeks. You may not be able to go back to work since you will still be wheelchair dependent when you return home for at least one month. Prepare your finances so you can not only afford this surgery but also afford any possible complications from this surgery that can arise. These are not common but can be costly when they do occur.

Be prepared to be single minded and not distracted during the process so you can devote all your energies and attention to the limb lengthening process and rehabilitation.

Visit West Palm Beach and check out where you will stay and the lay of the land. Arrange for someone to come with you or be prepared to hire home health to help you (see separate section on this).

Organize a leave of absence from your job so that you don't feel the pressure of the need to get back to work.

**Do I need to book a consultation before surgery?**
Yes. Although the information provide via email is very educational, we need to assess you and you need to become as prepared as possible for the surgery. We have found that patients who do now come for a consultation are not as prepared for the surgery and have much more difficulty when they undergo this procedure.

**How do I book a consultation?**

Please call the Paley Advanced Limb Lengthening Institute 877 765-4637 (Toll Free) 561 844-5255 (Main). You may also contact Caroline Eaton our patient coordinator ceaton@lengthening.us (561-307-8703).

**What is the cost of surgery and physical therapy?**

The cost of surgery with physical therapy is $90,000 for bilateral femoral lengthening and $100,000 for bilateral tibial lengthening. For individuals who undergo femoral lengthening followed by tibial lengthening we offer a package price of $180,000.

**Can I get financing to help pay for the surgery?**

We do not provide financing. However, we can give you the name of one or two financing companies to contact directly. For this info please contact our practice administrator Ali Birjandi abirjandi@lengthening.us (561-310-8076)

**What is covered in the cost of surgery?**

1) Hospital stay for up to 4 days. There is a surcharge for patients staying longer than this
2) All hospital charges relating to the operating room and recovery room
3) Two PRECICE lengthening rods
4) Anesthesiologist fees
5) Surgeons fees
6) Surgery assistant fees
7) Hospitalist fees (internal medicine doctor available during the entire hospital stay)
8) Radiologist fees
9) All x-rays for 10 weeks (surcharge after 10 weeks)
10) All office visits for 10 weeks (surcharge after 10 weeks)
11) All daily lengthening adjustment sessions with our orthopedic technologist (including on weekends)
12) Transportation to and from the office and hospital for office visits if you stay at one of the approved extended stay hotels (on weekdays only).
13) Wheelchair, walker and bedside commode as needed for post surgery.

**What is covered in the physical therapy fees?**

1) Daily, 5 days per week, one hour of physical therapy at the PALLI outpatient rehab center. (there is no PT on weekends) for up to 9 weeks. Surcharges apply to longer than 9 weeks of PT.
2) Transportation to and from the PT center, located next to my office.

**What is not covered?**

1) Medications and pharmaceuticals (pain medicine and anticoagulants)
2) Accommodations in West Palm Beach
3) Travel to and from WPB
4) Travel to the hospital on weekends (although the hotel shuttles will usually provide this for free)
5) Food and other supplies during the stay in WPB
6) Entertainment or Internet
7) Home health aids (nurses, homemaker, etc)

**When do I have to send the payment and do I need to leave a deposit to hold the surgery date?**

Full payment is due two weeks before surgery or the surgery will be cancelled. Payment can be made by wire transfer or certified check but not by credit card. A non-refundable deposit of $10,000 is due one month before surgery between September to April (offseason). From May to August (season) the deposit must be made at the time of booking due to the high demand for operating room time. The deposit can be made by credit card on the phone or by wire transfer. We will not hold a surgery date within a month of surgery without a deposit during the offseason. Cancellation of the surgery with less than one month notice during the offseason and two months notice during the season results in loss of the deposit. The deposit money is part of the total fee and will be credited to the amount due.

**How much money should I keep in reserve in case of complication?**

Complications although infrequent can occur and may require surgery to treat and to prevent a negative outcome. An example is premature consolidation of the bone which requires rebreaking the bone. Another is nerve entrapment which requires nerve decompression. Another is muscle contracture which requires lengthening of muscles, tendons or fascia. Finally there can be failure of bone healing after the end of the distraction phase requiring repair of nonunion. The cost to treat most of these complications ranges from $12-$35,000.
What is the likelihood of complications that would require additional surgery?

The likelihood of complications that require additional surgery for treatment is less than 5%. Thus far none of the patients with the new PRECICE lengthening method have had a complication.

**Why do we not allow full weightbearing during treatment?**

During distraction the bone ends are held separated by the implantable rod. This rod is secured to the bone by screws at either end. The diameter of the rod ranges from 10.7-12.5mms. The screws have a diameter ranging from 4-5mms. With enough repeated loading the screws or the rod will bend or break. No implant is immune to this. The heavier the patient the greater this risk. Some surgeons permit full WB. This is a gamble. I have seen many patients who don’t protect WB and end up with bent or broken hardware or failure of union of the bone.

We permit full WB when we see complete bridging of the bone on the xray on at least one side of the bone. At that point the bone is taking the load and protecting the rod. During the lengthening we allow WB using a walker and unweighting the legs using the arms. This is only for a few steps from bed to chair or toilet, etc. The amount of unweighting using the arms depends on the body weight. Ideally each rod should not be loaded by more than 50lbs. That means we can allow standing of up to 100 lbs on both legs. Patients weighing under 100 lbs can walk full WB without unweighting. Patients weighing 150lbs must unweight 50lbs with the arms. Those weighing 200 lbs must unweight 100 lbs with the arms.

**How long is the hospitalization?**

The hospitalization is usually 3-4 nights. At St. Mary’s Hospital this is in a private room on the newly renovated surgical care unit in the Waters 3 Pavillion.

**Will I leave the hospital with a wheelchair and walker?**

Yes. You will be given a wheelchair and a walker to take with you. You will be taught how to do transfers to chair and toilet.

**Where will I stay after discharge from hospital?**

There are several options.

1) The most common place to stay is at one of our extended stay hotels which are on 45th St. This is a few miles west of the hospital on the same street as
the hospital. The cost of stay at these hotels is between $59 and $89 per night. Cost may vary with season. High season is winter and low season is summer.

(Shuttle service provided to hospital)
Homewood Suites By Hilton – 561-291-4414
Residence Inn By Marriott – 561-687-4747
Springhill Suites By Marriott – 561-291-4414
Extended Stay – 561-683-5332

(Near Airport)
Doubletree By Hilton – 561-689-6888

2) Renting a condominium or house.
3) Staying at another hotel.

Is transportation available to and from the hospital to place of residence?
Wheelchair transportation vans are available to take you to and from the hotel to the hospital only if you stay at the extended stay hotels listed above.

How long do I need to stay in West Palm Beach?
You need to stay until the end of the distraction phase (lengthening). The distraction phase length is one day for each mm of planned lengthening. E.g. 65mms = 65 days. We don’t start lengthening for 5 days. Therefore 70 days for 65 mms.

Will I need help to look after myself?
Yes. You either need to come with someone who can help look after you or else you will need to hire a home health aid. We can help you arrange for this. The hourly cost of this is approximately $18/hr. In the first week after discharge from hospital you will require more hours of help and less help as time goes on. You need to budget for this if you are coming alone.

Am I allowed to drive?
Patients undergoing implantable limb lengthening can drive once they are not taking narcotics during the day. They do however need to be able to get in and out of the car on their own. Stand up with a walker and transfer to a wheelchair on their own for complete independence.
**How often will I have physical therapy?**

Daily, 5 days a week for the entire distraction phase.

During consolidation phase the patient needs to continue with PT but less often (2-3 days per week).

Daily home exercises are required by the patient throughout both distraction and consolidation phases.

**How and where is the lengthening done?**

The lengthening is done by one of our specially trained ortho techs at the Paley Institute. They will apply the ERC device to the thighs or legs once or twice a day to perform the lengthening. At present the FDA does not permit the ERC device to be taken and used at home by the patient. We expect this ruling to change in the near future. It will allow a home health aid to administer the lengthening however and we are considering this method to allow for more independence.

**How often am I seen by the doctor or physician assistant?**

Weekly.

**When will I have x-rays done?**

Weekly one xray of each lengthening segment is taken.

**Once I am done lengthening how soon can I go home?**

Immediately.

**What is the followup after I go home?**

Send weekly x-rays to Dr. Paley. The best way is to email these to dpaley@lengthening.us. If you cannot figure out how to email x-rays mail the disc to:

Paley Advanced Limb Lengthening Institute

Kimmel Building,
When can I resume full weightbearing without support?

After reviewing the x-rays Dr. Paley will email you how they look and whether you can resume full WB. This usually happens after one month from the end of distraction.

When can I return to sports?

You have to regain your motion and then your muscle strength before returning to sports. If you work hard at this you can go back as early as six months after surgery. This is individualized by the doctor for each patient.

What are the results from internal lengthening of the femur?

I have performed implantable lengthening of the femur for 17 years, and have used the Alibizzia, the ISKD and now the Precice. I have the world’s largest experience with the ISKD and the Precice devices. To date all of my patients have achieved the goals of treatment and have returned to full activities including sports.

Do I need to have the nails removed?

Yes. All of these nails should be removed. Removal timing is not critical, but most often is done one year after the original surgery. The reason to remove the nails is that they are made from titanium and since they have moving parts and generate metal ions over the course of many years. While they are inert and there is no urgency to remove them it is recommended to remove them one or two years after insertion.

How soon can I have another lengthening (e.g. both tibias)?

If you choose to have a second lengthening done. An interval of six months is the minimum between lengthenings.

What are the main potential complications that can occur?
No one wants unexpected problems, complications and costs. For these reasons I am very conservative regarding many aspects of the limb lengthening process. I try and anticipate problems and prevent complications. Many complications lead to additional surgery and therefore to additional costs. The following is a list of some of the potential complications:

Fat Embolism

This is a complication that is very rare and which can be prevented by venting the bone during the reaming (drilling) of the medullary canal of the bone. The way I vent the canal is to drill holes at the planned level of the osteotomy prior to the reaming process. As the pressure builds up in the canal the reamings squirt out the holes preventing fat embolism. Fat embolism can make a patient very sick requiring stay in the ICU. Patients can even die from fat embolism. I have only seen fat embolism twice in my patients. Both occurred more than 10 years ago before I developed a special venting method to prevent this complication. Fortunately both patients recovered uneventfully. I have never had a patient die from this procedure!

Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)

DVT can occur after any orthopedic surgery or after any fracture. Fortunately we have a very low rate of this complication. Prevention is key. We use anticoagulants after surgery in the hospital and each patient is sent home with a prescription for an anticoagulation drug to be taken until the end of the distraction phase. The cost of this medicine must be borne by the patient and is not included in our cost estimate. While I have seen very few cases of DVT fortunately none of them resulted in PE. PE occurs if the clot dislodges and wanders to the lungs. It can cause shortness of breath, chest pain and even death. This is why we are careful to protect against this. Taking oral contraceptives and smoking increases the risk of DVT.

Premature consolidation: in this complication the patient bone bridges the gap and prevents further lengthening. Premature consolidation (PC) can occur with any method if the patient is a very rapid bone healer. The patient in these cases is able to make bone faster than the speed at which the bone is being lengthened. The only way to prevent this is to speed up the lengthening intentionally for a week or two. The Precice nail with its rate control allows the surgeon to do this. If premature consolidation does occur it requires an outpatient small surgery to rebreak the bone through a tiny incision.

With the ISKD and Albizzia premature consolidation was a well recognized complication due to the lack of control of rate of lengthening. Since lengthening in both of these devices occurred by movement through the osteotomy site and since movement through the osteotomy site can cause pain and muscle spasm, the
patients muscles sometimes would prevent the movement and therefore the lengthening from occurring. In other cases both the ISKD and the Albizzia have had broken mechanisms that fail to lengthen during the distraction phase leading to PC. The treatment in these cases was to not only rebreak the bone but also to change the device to a new device. Although in each such case the company provided a new device at no additional cost, the patient still had to bear the cost of an additional outpatient surgery.

Delayed or failure of consolidation: slow or failed bone healing can occur with any lengthening surgery. This complication can usually be prevented by making drill holes at the level of the planned osteotomy before reaming the bone. This is a technique I introduced in 1990 with the lengthening over nail method. Stable fixation is also important so the choice of nail length and diameter are important as well as the level of the osteotomy. Even the type of osteotomy affects the rate of bone healing. Cutting the bone with multiple drill holes and an osteotome is the most minimal invasive way while using an intramedullary saw or performing an open osteotomy have higher failure rates. All of these are surgeon controlled parameters and are based on surgeon knowledge and experience. Choosing the wrong level or method of osteotomy or the wrong diameter or length of implant can significantly impact the result. Perhaps the most important parameter however is the rate of distraction. Lengthening too quickly can lead to delay or complete or partial failure of bone formation.

Too rapid distraction is the most common cause of poor bone formation with the ISKD. This is not a problem with the Precise since it has complete rate control. Poor bone healing can be recognized during the lengthening process. Once it is recognized the rate of distraction should be slowed. Slowing the distraction is difficult with the ISKD. It requires the patient to stop physical therapy, get into bed and decrease mobility and wear a brace from the hip to the ankle. With the Precise the lengthening can be reduced to any level or even stopped. If despite these changes the bone healing remains poor, the lengthening can be reversed until better bone formation is seen. The bone can then be relengthened. This can only be done with the Precise. Going reverse is not possible with the ISKD, Albizzia or the Fitbone. This is a huge advantage that was only possible before with external fixation.

Delay or failure of bone formation can delay weightbearing and increase the period of disability and recovery. Furthermore it can lead to the need for surgery to get the bone to heal. Such surgery requires a bone graft and is not a small operation and can be quite costly. Therefore having a device like the Precise that can prevent or treat the problem is a major advance.

Nerve injury: nerve injury can occur with any lengthening surgery but is usually uncommon if the rate of distraction does not exceed 1mm per day and if the amount of lengthening is restricted. Rate control is the most important factor to prevent nerve damage. Recognition of nerve symptoms is important. The lengthening should be stopped or slowed in such cases. If any motor symptoms (weakness or paralysis of muscles) occurs a nerve decompression should be done as soon as possible. This
is a small outpatient surgery. In most cases it is the peroneal nerve that gets into trouble. It is important that the surgeon know how to decompress this nerve to prevent foot drop. Delay in decompression can lead to permanent foot drop.

The ISKD too rapid distraction has lead to nerve complications in some patients. For this reason I will not lengthen more than 5cms with the ISKD. With the Precice and complete rate control, nerve injury should be much less common and greater lengthening can be performed safely.

Muscle contractures: muscles normally get tight with lengthening. A muscle contracture occurs when a muscle gets tight enough to prevent a joint from moving through its entire range of motion. To prevent muscle contractures physical therapy (PT) is essential. The patient should do daily stretches of the muscles and joints at risk. E.g. knee joint and quadriceps muscles for femur lengthening and ankle joint and Achilles tendon for tibial lengthening. In addition to formal PT the patient should do their own stretches at home several times per day. PT is essential to the lengthening process. It is however expensive. I will not consider doing a lengthening if a patient is not willing to do PT. This is not an option for reducing cost. Too rapid distraction with the ISKD made PT even more difficult. We frequently had to suspend PT to slow the distraction. We also had to fight muscle spasm due to the constant bone movement with the ISKD. For this reason we started using Botox to prevent spasm with ISKD. Botox is very expensive. It is usually not necessary if the rate of distraction is controllable. Once again the controlled rate of lengthening with the Precice makes the risk of muscle contractures and muscle spasm less. I do not routinely use Botox with the Precice which is another cost savings. The Precise does not obviate the need for PT. Maintaining range of motion and preventing contractures during lengthening decreases the rehabilitation time to return to normal function after the lengthening is finished. A fixed contracture of the knee or ankle can lead to disability and the need for more prolonged PT and the expenses associated. If despite additional PT the contracture does not resolve additional surgery to lengthen muscles, tendons and fascia may be required. I try and anticipate this and prophylactically lengthen certain soft tissue structures to prevent contractures (e.g. iliotibial band). If this is done at the initial surgery the additional cost is small. If soft tissue lengthening surgery is required at a later date the cost is much higher since one also has to pay for the hospital costs.

Fibular complications: with tibial lengthening the fibula has to be lengthened too. The implantable lengthening device only lengthens and fixes the tibia. The fibula has to be fixed to the tibia so that it lengthens together with it. If the fibula is not fixed or not fixed adequately it will not lengthen as much as the tibia and will lead to severe consequences including subluxation and arthritis of the ankle and flexion contracture of the knee. The method of fixation is critical. Many surgeons only fix the lower end of the fibula to the tibia. This can lead the fibula to prematurely
consolidate and to pull down and dislocate from the tibia at its upper end. It is important to fix the fibula at both ends. With external fixation the fibula can be fixed with the wires of an external fixator. With implantable lengthening the fibula must be fixed with screws to the tibia; one screw at the upper end and one at the lower end. The angle, level, position, diameter, and type of screw are all important. E.g. a common mistake is to put the screw in horizontally between the two bones. This is not strong enough to prevent the fibula from pulling away from the tibia at the ankle. This is very subtle and even a few millimeters of difference in length of the fibula at the ankle lead to short term and/or long term consequences for the patient. Removing a segment of the fibula to prevent the fibula from not separating is another common method that should be abandoned. It leads to a nonunion of the fibula which can lead to a stress fracture at a later date in the tibia. Furthermore it usually does not prevent the fibula from pulling away from the tibia. Therefore fibular complications have nothing to do with the type of implantable lengthening device but rather with the method the surgeon chooses to fixate the fibula to the tibia and the method of cutting the fibula bone.