

A Human Gait Institute Publication



## **EXPLORING LEG BRACING OPTIONS**

Thoughts, considerations, and references

This document draws on the experiences of those of us who continue to actively explore bracing options with the goal of improving the quality of life of those impacted by musculo-skeletal limitations.

[www.humangaitinstitute.org](http://www.humangaitinstitute.org)

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## Foreword

Exploring Leg Bracing Options is a workbook produced by The Human Gait Institute in accordance with its Mission Statement, which states:

*The mission of the Human Gait Institute is to assist people in reaping the benefits of innovative lower extremity orthotic technologies by supporting and/or conducting research, by fostering education and training for orthotists in these technologies, and by providing resources to support patients who are considering or using these technologies.*

The **Human Gait Institute** (“HGI”) was organized April 11, 2008. It is a Colorado non-profit corporation. It has obtained tax exempt status under Section 501(c)(3) of the federal Internal Revenue Code.

HGI is governed by its five Board members who have a combined 150 years of wearing leg braces, buying over 35 different types of braces. The Board members have gone through the process of obtaining leg braces in some form over these years. They currently all use innovative bracing technology.

The workbook is intended to be copied for personal use only. No part of it can be sold for profit. However, donations to HGI to help defray the cost of the workbook are greatly appreciated.

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## I. Introduction

### Getting a new leg brace – Do your homework!

Getting a new lower extremity leg brace is usually the result of either a long-term disability or a recent event that has compromised one's mobility. Bracing options can be as simple as providing temporary ankle support or as complex as a computerized electronic "exoskeleton". Regardless of the brace chosen, the goal should be to optimize physical functioning.

Acquiring a new brace is not unlike acquiring a car. There are, in the orthotic market place, high-end luxury models that have top of the line options with all the bells and whistles, and there are braces that do not do what they say they will do and do not offer any remediation for the problem they are supposed to address. Like a well-informed car buyer, a well-informed brace buyer should research the options to see which provide the best solution to their problem before investing in a new brace.

Whether being fitted for a leg brace for the first time or getting a replacement for a current brace, it is important to carefully evaluate your current situation and determine your goals. These may include such things as

Standing at the kitchen counter	Walking short distances outdoors
Transferring to a chair more easily	Hiking, biking, or other recreational sports
Standing and talking to friends	Participating in exercise programs
Walking short distances indoors	Limiting the use of assisted devices like canes

There are also many personal, social, emotional, and financial impacts to consider. For example, insurance may limit choices or may only cover a part of the cost of a brace. Being aware of these potential impacts and giving serious consideration to your specific needs, desires, and goals and then addressing them up front can be helpful in making a smooth transition from what is to what will be.

This workbook is divided into 10 sections. The checklists do not have to be completed in any specific order and may be revisited as new information becomes available.

- Personal and lifestyle considerations
- Limitations and modifications
- Questions for the service providers
- Shopping for a brace - brace function questions
- Shopping for a brace - brace construction questions
- Shopping for a brace - shoe considerations
- Shopping for a brace - cost considerations
- Appendix -including a list of resources and a glossary

In addition to this workbook, HGI has a document, "Considering Custom Leg Bracing" on its website ([www.humangaitinstitute.org](http://www.humangaitinstitute.org)).

## II. Personal and lifestyle considerations

Knowing the diagnosis of my condition, its impact on my mobility, and the symptoms that I have help determine the optimal brace for my needs. Some diagnoses that have resulted in the need for lower extremity bracing include, but are not limited to: traumatic injury from an accident or as the result of surgery, peripheral neuropathies, stroke, the after effects of polio (Post-Polio Syndrome or PPS), Multiple Sclerosis (MS), Charcot-Marie Tooth (CMT).

Some of the diagnosed conditions may be temporary and some may be long-term, perhaps lasting a lifetime. Also, some conditions may stay the same or may progress over time.

### A. Diagnosis

What is the diagnosis that has warranted me considering getting a brace?

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### B. Condition

What is my understanding of my condition?

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### C. Symptoms—general

What issues do I have with mobility/muscle weakness?

1.  Drop foot—Do I have difficulty lifting my foot that results in catching my toes on the ground?
2.  Ankle—Does my ankle rollover or collapse?
3.  Knee—Does my knee buckle/fail to hold me up?
4.  Knee—Does my knee bend backward (hyperextension) and/or move side to side?
5.  Knee—Do I need to place my hand on my thigh to stand or walk?
6.  Strength—Am I experiencing a decrease in strength/stability in my extremities (leg, hip, ankle, knee)?
7.  Functional Skills—Have I noticed a difference in functional skills (such as: driving, navigating stairs)? \_\_\_\_\_

**D. Symptoms—falling**

1. \_\_\_\_\_ Do I have near falls?
2. \_\_\_\_\_ Do I fall? If yes, how frequently? \_\_\_\_\_
3. \_\_\_\_\_ Does falling cause me or others concern?
4. \_\_\_\_\_ If I do not fall, am I afraid of falling?
5. \_\_\_\_\_ Direction of fall(s) (forward, backward, side)? \_\_\_\_\_
6. \_\_\_\_\_ When I fall am I able to get up without assistance?

**E. Symptoms—balance**

1. \_\_\_\_\_ Do I have difficulty keeping my balance?
2. \_\_\_\_\_ If yes, has the cause(s) been identified? \_\_\_\_\_
3. \_\_\_\_\_ Have I consulted a professional to help me improve balance?

**F. Symptoms—pain**

1. \_\_\_\_\_ Am I considering bracing to address pain issues in the back and/or the lower extremities? \_\_\_\_\_
2. \_\_\_\_\_ Where is my pain located? Left, right, both sides? Back, hip, knee, ankle, foot?  
\_\_\_\_\_
3. \_\_\_\_\_ Does pain affect my mobility? \_\_\_\_\_
4. \_\_\_\_\_ Has any kind of external support helped my pain previously?  
\_\_\_\_\_
5. \_\_\_\_\_ Temporary pain or discomfort can be part of learning and adapting to a new brace. Do I think I will be able to tolerate the discomfort until I adjust?
6. \_\_\_\_\_ If the brace realigns my foot/leg structure, it may cause pain until my body adjusts. What resources do I have for addressing this?  
\_\_\_\_\_

**G. Symptoms—fatigue/endurance**

1. \_\_\_\_\_ How far long can I walk before tiring? \_\_\_\_\_
2. \_\_\_\_\_ How long can I stand before I need to sit? \_\_\_\_\_
3. \_\_\_\_\_ Has there been a decrease in my activity level that has affected my life style? \_\_\_\_\_
4. \_\_\_\_\_ Do I become so fatigued that my concentration, mental acuity is compromised? \_\_\_\_\_

### III. Limitations and modifications

Although wearing a brace might be able to help mobility, there may also be other issues that need to be addressed. Addressing these issues and setting personal goals can help provide direction about whether any brace, a specific brace, in combination, perhaps, with assistive devices (canes, crutches, etc.) is the best solution for my needs. Also, these issues might be able to be addressed with modifications to my current brace.

#### A. Physical factors

Each of the following conditions indicates the possibility of limiting the type of brace that can work for me: spasticity, flaccidity, neuropathy, muscle weakness, or body structure deformity.

1. \_\_\_\_\_ Does my condition include any of the above? \_\_\_\_\_
  2. \_\_\_\_\_ Am I or can I become physically strong enough to carry the weight of the brace?
  3. \_\_\_\_\_ Do I have any skin sensitivities that might limit the type of materials used in the brace? \_\_\_\_\_
  4. \_\_\_\_\_ Has my provider addressed these issues with me to help me decide which brace is best for me? If so, how?
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#### B. Cognitive, emotional, social, cultural factors

These factors may influence my decision on getting a brace or they may indicate that special modifications need to be made to have the brace work for me. For example:

1. \_\_\_\_\_ Dependency—Aversion to, or disliking the idea of having to depend on a brace
2. \_\_\_\_\_ Cosmetic issues—The brace looks ugly, “medical,” or bulky, does not look good with my clothes, or other related concerns.
3. \_\_\_\_\_ Shoes—How shoes look and feel is important. (See section VII)
4. \_\_\_\_\_ Time and energy constraints—The brace may take time and effort to learn to use, including putting it on and taking it off.
5. \_\_\_\_\_ Certain activities may require removal of the brace.
6. \_\_\_\_\_ Weight—The brace weighs too much and/or is clunky. I don’t have the physical strength and energy to walk in the brace.
7. \_\_\_\_\_ Lifestyle and cultural issues—Family custom or practice is to not wear shoes in the house. Some families/cultures would frown upon or discriminate against people who wear braces.

**B. Cognitive, emotional, social, cultural factors (continued)**

8. \_\_\_\_\_ Driving—Adaptions may be required to operate a motor vehicle.
  9. \_\_\_\_\_ History—Long held or strong negative feelings about using a brace.
  10. \_\_\_\_\_ Financial considerations—consider the relative value of the cost of bracing and its benefits in relation to my other financial priorities.
  11. \_\_\_\_\_ Other personal, social, cultural issues \_\_\_\_\_
- 

**C. Possible trade-offs**

Potential new brace wearers may find that there are activities they may have to do in different ways than previously. This may include some aspects of mobility or ease of activity, such as gardening or driving. Also, some muscles may be used in new ways.

**D. Alternatives**

Have I considered other alternatives to bracing, such as surgery, wheel chair/scooter, crutches, canes, and walkers? What are my reactions to these alternatives?

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**E. Shoes**

How hard are they to acquire? How to find them? Cost? Appearance? (See also section VII)

**F. Clothing**

Selection of style (for example, skirt length or width of pant leg) and some fabrics may not work with certain braces.

**G. Other personal/lifestyle concerns**

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## IV. Questions for the service providers

Choosing experienced, competent providers (physician/orthotist/physical therapist) to assist me in the process of evaluating and selecting an appropriate bracing option is critical. Finding these providers can require significant effort (there is listing of some possible resources to aid me in this process in the appendix). It is also important to find out if my current healthcare insurance has any restrictions related to providers.

### A. Current providers

What are my choices? \_\_\_\_\_

Who are my current providers? \_\_\_\_\_

### B. Qualifications

What are the general qualifications of the orthotist or service provider, including education, training, experience, licensure, and/or certification.

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### C. Experience with the brace under consideration

1. What are the provider's specific qualifications and training in the fitting and manufacturing of the brace being considered?
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2. \_\_\_\_\_ Is the provider interested and/or trained in making and fitting innovative braces/orthoses, and willing to do so?

### D. Commitment

What is the provider's commitment to taking the process from start to finish?

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### E. References

1. \_\_\_\_\_ Can the provider give references for some wearers who have had experience with the specific kind of brace I am considering?

2. What does the process of being fitted entail (number of visits and time required)? \_\_\_\_\_
- 

### F. Follow up after delivery

1. \_\_\_\_\_ Is there care and follow-up after the brace is delivered?

What services does that include? \_\_\_\_\_

For how long after the brace has been delivered? \_\_\_\_\_

2. \_\_\_\_\_ Is there additional cost for the aftercare services? \_\_\_\_\_

3. \_\_\_\_\_ Does the provider recommend post purchase aftercare visits to check fit?

4. \_\_\_\_\_ Does the provider address shoe issues such as recommending special shoes or special shoe modifications (see Section VII)?

**G. Modifications**

1. \_\_\_\_\_ Can the provider make modifications to the brace over time?
2. What kind of modifications are possible? \_\_\_\_\_
  
3. How extensively can the brace be modified? \_\_\_\_\_
4. Are there additional fees for making these modifications? \_\_\_\_\_

**H. Repairs**

1. \_\_\_\_\_ In the case of damage, can it be repaired instead of being replaced?
2. What kind of repairs are possible? \_\_\_\_\_
3. \_\_\_\_\_ If so, are these repairs covered by insurance?

**I. Alternative orthotist / providers**

What are the alternatives if the service provider is no longer available?

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**J. Training**

1. \_\_\_\_\_ Is training in wearing the brace required or recommended? If so, what is an estimate of the time commitment and for how long?  
\_\_\_\_\_
  
2. \_\_\_\_\_ Does the provider do the training or are the services of another professional, such as a physical therapist recommended?
3. \_\_\_\_\_ Will insurance cover the training by the orthotist?
4. \_\_\_\_\_ Will insurance cover the services of the physical therapist, and for how many visits? \_\_\_\_\_

**K. Other service provider questions**

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## V. Shopping for a brace—brace function questions

Before getting a brace, knowing how the recommended brace works and how it can be used to achieve my specific goals will help me anticipate what is involved in using the brace.

### A. Mechanically

1. Does the brace have:

- Some moving parts?
- Some of its joints stationary/fixed?
- Some combination of these?
- Moving parts than can be adjusted?
- Materials that will deteriorate with use and need to be replaced?

2. Does the brace have components that aid walking?

- Dynamic component?
- Electronic component?
- Do these components facilitate a natural gait?
- Does it feel unnatural or awkward to me?
- If it does feel awkward, is it possible to handle this issue through practice or physical therapy?
- Does the brace have a locking knee or ankle joint?
- If so, which one or both? \_\_\_\_\_
- Can the joint(s) be adjusted to limit movement?
- Can I do adjustments and minor repairs myself, (such as springs, joint bolts, Velcro replacement)?

3. Relationship to symptoms, deficits, and challenges. Does it address concerns?

- At the foot?
- At the ankle?
- At the knee?
- At the hip?

How does it do so in each of these areas?

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**B. Physical functionality**

How does it work?

1. What bio-mechanical principles are utilized in the brace to hold me up?  
\_\_\_\_\_

2. What components help me walk?  
\_\_\_\_\_

3. \_\_\_\_\_ Is the brace strong/robust enough to support my weight?

4. \_\_\_\_\_ Will it improve my balance? How? \_\_\_\_\_

5. \_\_\_\_\_ In addition to the brace, will I also need to use a cane or cane(s), crutches, a walker, or other assistive device(s)?  
\_\_\_\_\_

\_\_\_\_\_ Is the use of these acceptable to me?

\_\_\_\_\_ Will use of this assistive device likely be short term or long term?  
\_\_\_\_\_

\_\_\_\_\_ Are my hands, arms, shoulders capable of using such devices?

**C. Meeting expectations**

In general, can I determine if the brace will do what it claims it will do?

1. How does it do what it says it will do? \_\_\_\_\_

2. \_\_\_\_\_ Is there any way for me to tell if it will do what it claims it will do prior to purchase? \_\_\_\_\_

**D. Ease of use**

1. \_\_\_\_\_ Will it be challenging for me to put on and to take off?

2. \_\_\_\_\_ Will it be challenging for me to learn to use?

3. \_\_\_\_\_ Will it require an acceptable amount of time to learn to use it?

4. \_\_\_\_\_ Will I need professional help, such as physical or occupational therapy, to be functional or proficient in using it?

5. \_\_\_\_\_ If I need physical therapy to be proficient in using it, approximately how much will be needed? \_\_\_\_\_

6. \_\_\_\_\_ Do I know what questions to ask to find the most appropriate physical therapist or occupational therapist?

**E. Daily activities and special events**

While wearing the brace, will I be able to:

1. \_\_\_\_\_ Go up and down stairs?
2. \_\_\_\_\_ Walk up and down slopes?
3. \_\_\_\_\_ Walk on uneven terrain?
4. \_\_\_\_\_ Drive?
5. \_\_\_\_\_ Run?
6. \_\_\_\_\_ Walk on Gravel?
7. \_\_\_\_\_ Actively participate in various sports and athletic activities that interest me? Examples: golf, swimming, hiking, snow shoeing, basketball, mountain climbing, cycling, other physically challenging activities.

**F. Other functional concerns**

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## VI. Shopping for a brace—brace construction questions

Knowing how a specific kind or style of brace is made has a significant impact on comfort, functionality, adjustability, and, care and maintenance.

### A. Brace options

1. \_\_\_\_\_ Ankle brace
2. \_\_\_\_\_ Ankle-foot orthosis (AFO)
3. \_\_\_\_\_ Knee-ankle-foot orthosis (KAFO)
4. \_\_\_\_\_ Knee brace (KO)
5. \_\_\_\_\_ Other \_\_\_\_\_

### B. Brace Materials

1. \_\_\_\_\_ Aluminum
2. \_\_\_\_\_ Electronic components
3. \_\_\_\_\_ Foam padding
4. \_\_\_\_\_ Graphite
5. \_\_\_\_\_ Carbon fiber
6. \_\_\_\_\_ Leather
7. \_\_\_\_\_ Leather straps and buckles
8. \_\_\_\_\_ Polypropylene plastic
9. \_\_\_\_\_ Steel
10. \_\_\_\_\_ Titanium
11. \_\_\_\_\_ Velcro (hook and loop) fabric straps
12. \_\_\_\_\_ Are my hands able to put on and fasten the brace straps?
13. \_\_\_\_\_ Am I allergic/sensitive to any of these materials? \_\_\_\_\_
14. \_\_\_\_\_ Other \_\_\_\_\_

### C. Weight

1. \_\_\_\_\_ What is the approximate weight of the brace? \_\_\_\_\_
2. \_\_\_\_\_ Do you and your provider, think this weight is manageable?

### D. Strength and durability

1. \_\_\_\_\_ Is it durable? How long can I expect it to last? \_\_\_\_\_
2. \_\_\_\_\_ Does it have a warranty? If so, how long is the warranty? \_\_\_\_\_
3. \_\_\_\_\_ What does the warranty cover? \_\_\_\_\_
4. \_\_\_\_\_ Can it be repaired?
5. \_\_\_\_\_ Can I do some of the repairs and maintenance myself? \_\_\_\_\_

D. Strength and durability (continued)

6. \_\_\_\_\_ Can it carry my body weight? What is the weight it can safely handle? \_\_\_\_\_
7. \_\_\_\_\_ Is the support adequate? Will the support be: back of the calf or thigh or front of the calf or thigh? \_\_\_\_\_
8. \_\_\_\_\_ Will it hold up for my desired physical activities?
9. \_\_\_\_\_ Will it feel safe for me? Will I have concerns that it will break?
10. \_\_\_\_\_ Do I have a backup in case the new brace is unavailable?
11. Shoes (Also see Section VII)  
\_\_\_\_\_ Can the brace be worn without shoes?  
\_\_\_\_\_ If so, is it slick on the bottom of the footplate?  
\_\_\_\_\_ Does it require special shoes, or shoes with special characteristics?  
If so what are these characteristics? \_\_\_\_\_
12. Care and maintenance  
What are the care and maintenance requirements to keep it functional?  
\_\_\_\_\_

13. Wearing the brace  
What does it look like?  
\_\_\_\_\_

How does it stay on the limb/what holds it to the body?  
\_\_\_\_\_

- \_\_\_\_\_ Is it visually acceptable to me?  
\_\_\_\_\_ Am I or my healthcare provider aware of other limitations that might affect my ability to put it on and take it off (hand strength, ability to learn new things, limitations in movement)? \_\_\_\_\_  
\_\_\_\_\_ Is a trial brace available?
14. Any other construction concerns?  
\_\_\_\_\_  
\_\_\_\_\_

## VII. Shopping for a brace—shoe considerations

Generally, shoes are an important part of how the lower extremity brace functions. Therefore, I will need to understand the shoe requirements when making my brace decision.

### A. Adapting to shoes

\_\_\_\_\_ Am I prepared to change from the kinds of shoes I have always worn, if required?

### B. Shoe size considerations

\_\_\_\_\_ Will the brace require a shoe size change or the use of split sizes? \_\_\_\_\_

### C. Shoe construction considerations

1. \_\_\_\_\_ Are special shoes needed to work with the brace?

2. \_\_\_\_\_ Are shoes with special characteristics such as a flat sole, deep heel cup, larger, deeper, or wider toe box, removable insole, cushioning or other characteristics required for the bracing system to work more effectively? \_\_\_\_\_

3. \_\_\_\_\_ Will I be limited in the kind and/or the style of shoe, such as dress shoes, limited heel height, slip-ons, sandals, slippers?  
\_\_\_\_\_

4. \_\_\_\_\_ Will shoes need to be modified to work with the brace?  
\_\_\_\_\_

\_\_\_\_\_ Is the sole of the shoe modifiable?

\_\_\_\_\_ Will insurance pay for the modification work?

### D. Shoe cost considerations

1. \_\_\_\_\_ Will the costs and the limitations of the shoe selections affect my decision regarding a brace?

2. \_\_\_\_\_ Am I willing/able to advocate for my needs in a shoe store?

## VIII. Shopping for a brace—cost considerations:

### A. Initial cost

1. \_\_\_\_\_ What is the initial cost of the brace? \_\_\_\_\_
2. \_\_\_\_\_ What portion will I owe? \_\_\_\_\_

### B. Additional cost(s)

Are there any additional costs beyond the cost of the brace itself, such as

1. \_\_\_\_\_ After-care services by the provider, including modifications/repairs  
If so, what are these services/costs? \_\_\_\_\_
2. \_\_\_\_\_ Physical Therapy? \_\_\_\_\_
3. \_\_\_\_\_ Travel costs? \_\_\_\_\_
4. \_\_\_\_\_ Special shoes? \_\_\_\_\_
5. \_\_\_\_\_ Special inserts and/or other orthotic inserts, such as a Solid Ankle  
Cushion Heel (SACH). \_\_\_\_\_
6. \_\_\_\_\_ Other assistive devices required (even temporarily, such as canes)?  
\_\_\_\_\_
7. \_\_\_\_\_ Training services and training equipment \_\_\_\_\_
8. \_\_\_\_\_ Video-taping or video-instruction available? \_\_\_\_\_
9. \_\_\_\_\_ Other considerations?  
\_\_\_\_\_
10. \_\_\_\_\_ Will insurance pay for any of these additional costs?  
If so, how much will it pay? \_\_\_\_\_

### C. Brace warranty

1. \_\_\_\_\_ Is there a warranty to cover replacement and/or breakage costs?  
What does the warranty cover? \_\_\_\_\_
2. \_\_\_\_\_ Is there an extended warranty available?  
What does an extended warranty cost? \_\_\_\_\_

**D. Insurance**

1. \_\_\_\_\_ Is the acquisition cost covered by insurance? If so, how much will it pay? \_\_\_\_\_
2. \_\_\_\_\_ Do I need to get insurance pre-authorization?
3. \_\_\_\_\_ Do I need to get insurance pre-certification?
4. \_\_\_\_\_ Is the provider approved by my insurance?
5. \_\_\_\_\_ Will the provider file the claim?
6. \_\_\_\_\_ If the provider doesn't file the claim, will the insurance company allow me to file my claim directly?
7. \_\_\_\_\_ Is the provider approved by my insurance for this kind of brace?
8. \_\_\_\_\_ Is there an appeals process if the brace costs are denied initially?
9. \_\_\_\_\_ Will my supplemental insurance pay for my claim if my primary insurance denies all or part of the claim?
10. \_\_\_\_\_ Is there a restriction on how often I can get a brace?  
If so, what is that period? \_\_\_\_\_

**E. Out of pocket payments**

1. \_\_\_\_\_ Is there an amount or percentage of the cost that is required up front? If so how much is this? \_\_\_\_\_
2. \_\_\_\_\_ Is a payment plan available?
3. \_\_\_\_\_ Do I have a Health Savings Account (HSA) or a Flexible Savings Account (FSA) account I can use?
4. \_\_\_\_\_ Will my total medical expenses in the current tax year (including the total cost of the brace) be high enough so a portion of the cost will qualify as a tax deduction (if I itemize)?

**F. Cost assistance**

\_\_\_\_\_ Are there other assistance programs available for the cost of the brace?  
If so what are these programs? \_\_\_\_\_

**G. Total costs**

What is the total cost to the wearer of getting the brace and being able to function in it? \_\_\_\_\_

**H. Loss/Damage Insurance**

\_\_\_\_\_ Can the loss of or damage to the brace be covered by homeowner/renter insurance or does it have to be scheduled or need a special rider?

**I. Other cost considerations**

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## IX. Summary

Getting a new leg brace can seem like a very challenging process because there are so many considerations. But it is a process that can and should be approached in a systematic and orderly fashion to insure the best possible outcome.

The good news is that there are a lot of innovative and exciting bracing options available today. Many incorporate new technologies that include sensors, lighter weight materials, and improved joints. Because of this, it is important to find and consult with medical professionals including your doctor, orthotist, and physical therapist.

“Do my Homework!”, so you can assess your individual requirements as you evaluate bracing options. The reality is that no one knows you better than you.

Completing the checklists provided in this workbook can help you begin your own process.

## X. Appendix

### A. Web Sites

Listed below are some websites that be helpful in researching bracing options. There are also many disease specific websites.

1. [\*\*www.post-polio.org\*\*](http://www.post-polio.org) This is the official web site for Post-Polio Health International in St. Louis, MO. It not only provides articles relevant to polio and Post-Polio Syndrome, but also lists locations of support groups, medical professionals, and book lists.
2. [\*\*www.polioplace.org\*\*](http://www.polioplace.org) Stories, video lectures on topics related to polio.
3. [\*\*www.eastersealscolorado.org\*\*](http://www.eastersealscolorado.org) At Easter Seals Colorado, there is a link to news about polio survivors in Colorado as well as a link to the latest issue of the *Colorado Post-Polio Connections* newsletter.
4. [\*\*www.poliotoday.org\*\*](http://www.poliotoday.org) Salk Institute for Biological Studies. PolioToday.org is designed to raise awareness of post-polio syndrome and to be a resource for polio survivors.
5. [\*\*www.survivorsofpolio.com\*\*](http://www.survivorsofpolio.com) Polio Survivors in the 21<sup>st</sup> Century is dedicated to polio survivors in the 21<sup>st</sup> century along with their families, friends and the medical community.
6. [\*\*www.international-post-polio-support.org\*\*](http://www.international-post-polio-support.org) International Post-Polio Support Organization Bulletin Board. A discussion forum and resource for current trends and research relating to polio and Post-Polio syndrome. You must join the group to participate.
7. [\*\*www.mayoclinic.org\*\*](http://www.mayoclinic.org) General website related to health issues, including polio, post-polio syndrome, vaccinations, and other related topics.
8. [\*\*www.newmobility.com\*\*](http://www.newmobility.com) The magazine and online site is devoted to active wheelchair users and encourages the integration of active-lifestyle wheelchair users into mainstream society.
9. [\*\*www.webmd.com\*\*](http://www.webmd.com) A general medical web site that has information related to polio, post-polio syndrome and other polio related topics.

### B. Books, DVDS, Videos

1. The Colorado Post-Polio Organization (CPO) has a lending library available to Colorado Support Group Facilitators, and post-polio survivors. To receive a complete list of resources available contact: Mitzi Tolman, CPPO Program Coordinator, at [mtolman@eastersealscolorado.org](mailto:mtolman@eastersealscolorado.org) or cell phone (720) 940-9291
2. ***The Polio Paradox***, 2002, Richard Bruno
3. ***Managing Post-Polio: A Guide to Living Well with Polio***, 2006, Lauro Halstead.
4. ***Post-Polio Syndrome: A Guide for Polio Survivors and their Families***, 2001.

\*DISCLAIMER: Health Care Professionals and web site referrals are submitted by Post-Polio individuals and are not endorsed or approved by either the Colorado Post-Polio Organization or Easter Seals Colorado. ALWAYS check with your personal physician for all medical questions, concerns, and referrals.

## XI. Glossary (terms used in this workbook)

### Charcot-Marie Tooth (CMT)

CMT is the most commonly inherited peripheral nerve disorder. CMT causes damage to the peripheral nerves, which carry signals from the brain and spinal cord to the muscles, and relay sensations, such as pain and touch, to the brain and spinal cord from the rest of the body.

### Flaccidity

Flaccidity is characterized by weakness or paralysis and reduced muscle tone without other obvious cause (e.g., trauma). This abnormal condition may be caused by disease or by trauma affecting the nerves associated with the involved muscles.

### Ankle foot orthosis (AFO)

Ankle foot orthosis (AFO) is commonly used to assist the ankle and allow the foot to clear the ground during the swing phase of walking. There are many varieties, most have a molded heel cup that extends behind the calf.

### Knee-ankle-foot orthosis (KAFO)

Knee-ankle-foot orthosis (KAFO) allows a patient to stabilize the knee and ankle. While it's very hard work, people using KAFO's, even those with no hip flexion, can take steps by swinging their legs while sometimes supported by forearm crutches. There are many types of KAFOs, including plastic and metal braces.

### Knee orthosis (KO)

A knee orthosis (KO) is designed to control knee and ankle motion. It extends from the upper portion of the thigh, crossing the knee and ankle, and terminating at the toes.

### Multiple-sclerosis (MS)

MS is a chronic degenerative disease of the central nervous system. Usually appearing in young adulthood and manifested by one or more mild to severe neural and muscular impairments, as spastic weakness in one or more limbs, local sensory losses, bladder dysfunction, or visual disturbances.

### Neuropathy

The term peripheral neuropathy has been used to refer to nerve damage that specifically causes pain in the shoulders, thighs, hips, or buttocks.

### Post-Polio Syndrome

Post-polio syndrome is a condition that affects the survivors of polio decades after the acute illness of poliomyelitis. Major symptoms include pain, fatigue, and weakness.

### Spasticity

This is a condition in which certain muscles are continuously contracted. This contraction causes stiffness or tightness of the muscles and can interfere with normal movement, speech, and gait. Spasticity is usually caused by damage to the portion of the brain or spinal cord that controls voluntary movement.