



# TOP 5 TSC TIPS

Top 5 Tips for Young Adults with TSC

# INTRODUCTION

When Novartis Pharmaceuticals Corporation approached me with its idea to develop a resource for adults living with tuberous sclerosis complex (TSC), we at the Tuberous Sclerosis (TS) Alliance were thrilled to support this project since, until recently, resources for adults affected by TSC were limited. Our organization is happy to partner with Novartis on this effort to provide additional assistance and information for those faced with the daily challenges of TSC.

*Top 5 Tips for Young Adults with TSC* is intended for individuals with TSC or caregivers who are looking for quick advice on ways to manage the disease from a physical, emotional and practical perspective. Dealing with TSC on a daily basis can be daunting for adults living with the disease and their caregivers, and I believe that using this guide in conjunction with other adult resources provided by the TS Alliance will help these individuals address and cope with common challenges.

I am especially thankful to TS Alliance constituents and colleagues who took time to provide invaluable feedback and insight to an initial draft of this guide in order to make it as helpful and relevant as possible to adults with TSC.

*Kari Luther Rosbeck  
President and CEO of the Tuberous Sclerosis Alliance*

# FOREWORD

I recently had a long conversation with a young woman with tuberous sclerosis complex (TSC) about her life and its challenges. In spite of many set-backs and ongoing physical issues, she had an incredibly positive outlook on life – accepting of those challenges, yet determined to lead a productive life with her TSC. She clearly had the sense of being in control, of feeling that whatever challenges are thrown at her, she has or will find a way to deal with it.

A well-known psychologist, Albert Bandura, coined the term ‘self-efficacy’ to describe an individual’s belief that they have the power and skills to manage their own lives. When people have a good sense of ‘self-efficacy’, they perform better, they take a broader view of challenges and tend to feel more self-motivated and healthy!

We can develop our self-efficacy by seeing others succeed, by being encouraged by others, and – most powerfully – by developing a sense of mastery through direct experience.

I sincerely hope that the tips provided in this little guide will help you in some way towards a sense of ‘self-efficacy’ in living a positive life with TSC.

*Dr. Petrus de Vries  
Developmental Neuropsychiatrist, University of Cambridge, UK*

# TIP 1:

## Be educated about manifestations – both physical and emotional.

Symptoms and manifestations of TSC usually change with age. For example, someone living with TSC may have experienced infantile seizures and subependymal giant cell astrocytomas (SEGAs) during childhood<sup>1</sup>. Other manifestations tend to surface with age such as renal angiomyolipomas, which typically occur between the ages of 15 and 30, with prevalence increasing with age. Doctors will help create and implement a management plan if a new manifestation surfaces<sup>2</sup>.

In addition to physical symptoms associated with TSC, there are also certain psychological, emotional, social and practical aspects typically associated with TSC and being informed about them might help manage these elements of living with the disorder. For example, many people with TSC may develop mood disorders. Research has shown that 45% of individuals with TSC develop anxiety and 29% report symptoms of depression<sup>3</sup>.

### Caregivers: “What are some signs of depression to watch for?”

Signs of depression differ from person to person, but in general may include, but are not limited to<sup>4</sup>:

- Feeling sad, down, hopeless, irritable, restless or helpless
- Losing interest in activities that were once source of pleasure
- Sleeping poorly or oversleeping
- Changes in appetite, or losing or gaining weight unintentionally
- Feeling fatigued or having decreased energy
- Having trouble thinking, concentrating or making decisions
- Abusing alcohol or drugs
- Suicidal thoughts

If there is a concern that a relative, individual or friend is suffering from depression (for example, if you notice a change in this person's usual mood or feelings over a period of a few weeks), it is important to talk to him or her, although he or she may feel ashamed or defensive. The topic should be broached in an open and non-accusatory manner, and caregivers should express their willingness to help in any way possible, such as offering to help identify a mental health professional. It is important to note that mental health professionals should be considered part of the multidisciplinary TSC healthcare team (and not only approached when there are signs of depression are)<sup>3</sup>.

# TIP 2:

## Assemble a multidisciplinary healthcare team.

Because TSC affects many parts of the body, individuals with the disorder will see many physicians who specialize in different manifestations. Specialists treating people with TSC include neurologists, dermatologists, nephrologists, urologists, pulmonologists, ophthalmologists, cardiologists, geneticists, pediatricians, internal medicine specialists, psychiatrists and psychologists. TSC management typically has the greatest success when a collaborative approach is taken by healthcare teams, with specialists connecting regularly to coordinate their patients' care<sup>5</sup>.

Medical teams, including mental health professionals, are available not only to help keep patients healthy but also to support them in coping with any fear, anxiety or stress. Even if the individual is not feeling emotionally distressed at the time, engaging their team is an important part of their care<sup>3</sup>.

### Questions to ask when considering a new physician.

If individuals with TSC need to find a new physician (for example, if they are transitioning from pediatric to adult care, they've moved or are newly diagnosed), here are some items to consider while making this decision:

- How long have they been practicing medicine/treating patients?
- What is their experience in treating people with TSC? What kinds of patients are they accustomed to seeing?
- If they do not have experience treating TSC, do they have access to resources or peers who can help support them?
- How accessible are they? How quickly can they fit in an appointment or be reached outside of office hours in the event of an emergency? Do they promptly return phone calls?
- Where are X-rays, MRI scans, CT scans and laboratory studies performed? Can they be conducted in-office or do patients need to travel to an outside institution?
- What insurance does the doctor take?
- Is the office conveniently located? What transportation options are available? Is parking provided for patients?

# TIP 3:

## Understand and track the treatment regimen.

Individuals with TSC who work with their healthcare team, including physician specialists, nurses, pharmacists and mental health professionals, will be able to better understand the objective of each medical appointment, procedure and option available.

People with TSC typically work with their doctors to track their medical history information carefully. It might be helpful to physicians to communicate openly about current and past management strategies and future treatment goals. This information will also be pertinent to new physicians<sup>3</sup>.

### There's an app for that!

With the emergence of the Internet and mobile health applications, there are many different types of digital tools available to help monitor and track medical history, appointments, medications and symptoms. For example, the **TS Alliance's Adult Journal** includes medical tracking advice and charts. There are also apps available that will help:

- Set reminder alerts to go to medical appointments, take medication or pick up a prescription
- Check symptoms
- View digital imagery results (like MRIs or X-rays)
- Store health data while traveling or for other uses

# TIP 4:

## Build a support network - look to family, friends or others with TSC for emotional support.

Building supportive relationships can serve as an important support network. A parent, sibling or caregiver who has been by an individual's side through his or her TSC journey can provide comfort as a trusted source. Even if they don't know the full history with TSC, friends or coworkers offer companionship so that people don't need to face life with TSC alone. Talking to others with TSC, especially for newly diagnosed adult patients, can also be helpful because it not only assures that they are not isolated in living with this chronic disease, but it can often lead to practical guidance about how to live with TSC on a daily basis. People with TSC can meet each other through online communities, social networking or local support groups<sup>3</sup>.

Many people living with TSC describe their involvement with a local TSC group as being a special part of their everyday life, since it can help develop a sense of community. Spreading awareness and education about TSC, while surrounded by people going through many of the same experiences, can contribute to a feeling of camaraderie and sense of self-empowerment. In addition, participating in online TSC conversations, via discussion boards or social media vehicles, can be a great way to find support and connect with others living with the disease. More information regarding local support groups and online resources can be found on the [TS Alliance's website](#).

Caregivers: "When a teenager with TSC is approaching adulthood and will soon need to transition from pediatric care, what ways are there to support them to make sure they continue to receive proper medical care?"

As teenagers transition from pediatric to adult care, one of the most important success factors is making sure that he or she will continue to receive comprehensive care<sup>5</sup>. Typically, pediatric TSC specialists are professionally equipped to treat all disease manifestations, but adult physicians usually specialize in manifestations associated with an organ/body system, such as the kidney (nephrologists) or central nervous system (neurologists)<sup>1,5</sup>. It is important for specialists to collaborate about teens' care and that they proactively recommend other specialists, as needed. For example, a mental health professional may be recommended since psychiatric conditions such as depression or anxiety sometimes develop in people with TSC as they reach adolescence and transition to adulthood. In addition, sometimes when individuals transition to caring for themselves, there can be disruptions in care for a variety of reasons<sup>6</sup> - perhaps the teenager was accustomed to having constant parental supervision and was not fully aware of all aspects of self-care, or the adult TSC specialists have not communicated with the pediatric specialist. If there is ever a concern that a child with TSC is not fully prepared to handle his or her own care, engaging extra advice from a professional caregiver can be helpful. For additional support in helping your teenager undergo a smooth transition from teen to adult care, refer to the TS Alliance's [Young Adult Guide of the Life Stages Program](#).

# TIP 5:

## Keep an open dialogue.

their life, such as requiring extra flexibility and understanding to accommodate medical appointments. People with TSC shouldn't be afraid to tell others that it is hard to share information about their journey with TSC, and it is okay to tell them it would be appreciated if they kept it to themselves as they will tell others in time. Telling someone about a sensitive issue can be difficult, but others will likely react compassionately. It may also be helpful to explicitly tell others what is needed from them to feel supported. Keeping an open dialogue with the healthcare team is also an important part of the TSC management approach for TSC patients. For example, this is especially important to consider as people with TSC transition from pediatric to adult care and new specialists who are not as familiar with treatment histories are engaged on the medical team<sup>6</sup>.

For adults who are newly diagnosed with TSC, initiating open discussions can be particularly helpful, since these individuals often have many questions and might be experiencing a range of emotions. Since TSC affects everyone differently, having personal and specific conversations about symptoms with healthcare professionals might help newly diagnosed patients embark on an effective management plan more quickly. Additionally, initiating open conversations with a support group or mental health professional about feelings related to a new TSC diagnosis might also help someone cope with the emotional elements of this news more effectively<sup>3</sup>.

Your employer is also someone you may consider discussing your TSC diagnosis with to ensure that he or she is aware of your condition and that you are afforded your rights. When you are applying for a job, make sure you are familiar with your rights under the Americans with Disabilities Act (ADA) as well as the Health Insurance Portability and Accountability Act (HIPAA). In short, under ADA, as long as you are qualified to do your job, your employer is legally required to accommodate your schedule based around your medical appointments, procedures and other health-related needs. You are NOT required to reveal you have TSC pre-employment at any time during your employment, and an employer cannot ask unless such an inquiry is job related or related to a business need. Additionally, understanding your health plan is essential when choosing a job and managing your finances. When speaking with a prospective or current employer, it might be helpful to ask if they offer a major-medical plan or managed-care plan, what the co-payment is for the plan or if it changes annually.

It is natural for those with TSC to shy away from discussing details about having TSC, but letting others (significant others, friends, coworkers) know can be important as the disease affects various aspects of

**To disclose or not to disclose – what questions to ask before deciding to tell a friend, co-worker or acquaintance about having TSC.**

Telling someone about TSC is a personal decision. Here are some questions to ask to ensure someone with TSC is comfortable opening up about the disease:

- Why do I want the person to know?
- What do I want this person to understand about TSC?
- Is it more important to me to explain what TSC is and what symptoms it causes, or to explain my own experience with TSC?
- What is the best way to deliver the information?
- What kind of response am I expecting?
- What do I think this person will do with the information I'll be sharing, and do I feel comfortable about it?



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