Pennsylvania Youth Leadership Network

Secondary Health Care Transition Toolkit

Developed by youth for youth

1st Edition
July 2009
PYLN

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PA Youth Leadership Network:

Who We Are

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What is the Pennsylvania Youth Leadership Network (PYLN)?

The mission of the PYLN is: " *To develop the self-determination, empowerment, and leadership of youth, that promotes successful post school outcomes in the areas of education, employment, independent living, and health and wellness among youth and young adults throughout Pennsylvania*." Furthermore, the purpose of *"this group is to foster an open dialogue with youth and young adults to create, enhance, or change important issues that affect their everyday lives including: transition from high school to adult life; policies and practices that affect individuals with disabilities; and promote the inclusion of youth and young adults with disabilities into all aspects of society at the national, state and local level."*

Since 2005 the goals of the PYLN have been:

1) Collectively work and collaborate with a variety of groups to ensure a successful transition of youth with disabilities.
2) Establish and maintain a mentoring coalition between youth with disabilities and young adults who have accomplished successful transitions.
3) Develop, distribute and implement self-determination/ empowerment resources for use in educational programs.
4) Develop a youth friendly disability resource guide/template that highlights basic definitions, general information regarding transition services, and resources at the state and local levels.
5) Ensure equitable policies, practices, and attitudes that affect individuals with disabilities.

To achieve these goals the Pennsylvania Youth Leadership Network has completed multiple activities, trainings, and documents throughout the past few years. Some of these have included: creating and managing all training and activities for youth at the following events: three Pennsylvania Statewide Transition Conferences, the Youth Outcome Expo, Temple University Institute on Disability C2P2 program, and the PA Statewide Independent Living Council's conference. We have also collaborated with other states to expand youth development and youth leadership efforts across the country.

Meet the PYLN members who contributed to the Toolkit

Josie Badger

Age- 25

Disability- Muscular Dystrophy

Location- Wampum, PA/Pittsburgh, PA

Activities- Josie completed graduate school for Rehabilitation Counseling at the University of Pittsburgh in May 2009. In May of 2007 she graduated summa cum laude from Geneva College, in Pennsylvania, majoring in Disability Law and Advocacy. On the state level, Josie is a founding member and youth coordinator of the Pennsylvania Youth Leadership Network. She is working with the Center for Disease Control and Prevention on a book addressing youth with disabilities transitioning out of high school. Josie is a member of the Governor's Council for People with Disabilities and the Pennsylvania Rehabilitation Council. She also works for the Pennsylvania State Implementation Grant to support youth in their healthcare transition.

Collan Baker

Age- 19

Disability- Aspergers Syndrome and Attention Deficit Disorder

Location- Bear Lake, PA

Activities- Collan currently attends the Hiram G. Andrews Center, in the Building Maintenance program. While in high school he was involved the high school chorus and in high school track for 5 years, lettering twice. He has been a junior counselor at the Gertrude Barber Institute and volunteered at Head Start. He received the Temple Grandin Award for his work and accomplishments. For the past three summers he has worked for Allegheny Coupling in Warren County.

Bond Collard

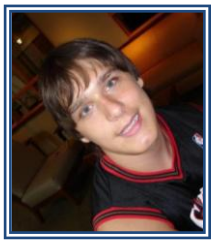
Age- 18

Disability- Asperger's Syndrome

Location- West Chester, PA

Activities- Bond Collard has been speaking publicly about his Asperger's Syndrome since 2005. He has presented at the National Autism Conference, the PA Community on Transition Conference, Center for School Mental Health Conference and others. Bond was featured in a 2007 Emmy-Award winning episode of Nick News entitled "Private Worlds - Kids With Autism". He volunteers at his local library and SPCA and works part-time at a CD manufacturing company. Bond is a member of the National Honors Society and will be entering his senior year of high school this fall. This is Bond's first year as a member of the PYLN governing board.

Lewis Hall



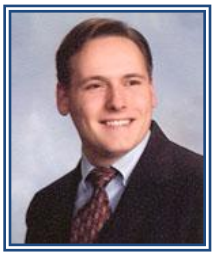
Age- 19

Disability- Cerebral Palsy

Location- Honeybrook, PA

Activities- Lewis currently attends college at Penn State Berks. Lewis has been involved in wheelchair sports for several years. He plays wheelchair basketball and wheelchair rugby. He has competed in the Devon Horse Show for twelve years and has won numerous awards. He also holds a green belt in Ti-Kwon-Do. Lewis has been completing his degree in accounting at a local college for the past year.

Jeff Hladio



Age- 28

Disability- Cerebral Palsy

Location- McMurray, PA

Activities- Jeff is involved in many activities inside and outside of the disability community. His hobbies include computers and sports. He works as a sales representative for Treasured Auctions (an online store). He has been a member of the Pennsylvania Youth Leadership Network since it began two years ago.

Rachel Kallem

Age – 24

Disability - Bipolar Disorder, ADHD

Location - Pittsburgh, PA

Activities - Rachel Kallem graduated from the University of Virginia in May 2007 where she majored in psychology and minored in anthropology. Rachel is currently pursuing her Master's in Community Mental Health/Special Education Support at Duquesne University. Rachel is co-chair of the National Youth Leadership Network's Public Outreach Committee and serves on the Governing Board of the Pennsylvania Youth Leadership Network. She currently works for Mental Health America – Allegheny County, doing disability advocacy work and outreach. Rachel also does work with the Allegheny County Coalition for Recovery (ACCR). In her spare time Rachel is a voracious reader and loves to spend time with her two cats, Celeste and Roxie, and guinea pig, Teadora Thunder Jackson!

Chaz Kellam

Age- 26

Disability- Osteogenesis Imperfecta

Location- Pittsburgh, PA

Activities- Chaz currently works with the Pittsburgh Pirates as the Manager of Diversity Initiatives within the Community and Public Affairs Department. After graduating from Edinboro University with a degree in Sports Administration, Chaz changed his focus and became dedicated to improving the quality of life for people with disabilities in the Pittsburgh region. Serving on several non-profit boards such as Consumer Health Coalition, UCP Pittsburgh, Achieva and others, Chaz is very active in the region trying to make a difference. In the summer of 2005, Chaz also became involved in semi-professional football working with the Pittsburgh Colts in a variety of front office capacities.

Joe Kleppick

Age- 23

Disability- Aspergers Syndrome, Attention Deficit Disorder

Location- Pittsburgh, PA

Activities- Joe serves on many different boards in the Greenfield Community and is also involved with many different political campaigns. He works at Wal-Mart currently. He has been an active member of the Pennsylvania Youth Leadership Network since 2006. He is a member of the PEAL Center Board and an advocate for youth with disabilities.

Kelly Lauth

Age- 24

Disability- Generalized Anxiety Disorder, Panic Disorder, Attention Deficit Disorder

Location- Pittsburgh, PA

Activities- Kelly graduated magna cum laude from Geneva College in May, 2007 with a degree in Communications and Theater, and a minor in music. She has won numerous awards for her dedication to the performing arts, such as winning the Junior Miss scholarship program for her county in 2003. She is a member of Alpha Psi Omega, an exclusive theater fraternity, and International Thespian Society. She is a member of the band The Manifolds, alongside her husband and brother-in-law, and has recently recorded a new album, on which she sings and plays guitar, piano, and drums.

Kate Matelan

Age- 21

Disability- Spinal Cord Injury—Quadriplegic

Location- Emmaus, PA

Activities-Kate Matelan is a senior at Bucknell University. She was recently named 2009 Ms. Wheelchair Pennsylvania, an award honoring the accomplishments of women with disabilities, and will represent the Commonwealth in the Ms. Wheelchair USA competition. Kate is a Business Management major with a minor in Legal Studies. She is the editor of *BE*, Bucknell's fashion magazine and this summer she is interning in the fashion industry in New York City. Kate is a strong advocate for individuals with disabilities with a platform that advocates for communication between students and faculty to identify barriers faced by college students with disabilities

Allison Mervis

Age- 24

Disability- Blindness

Location- Munhall, PA

Activities- Allison received a Presidential Merit scholarship and voice scholarship throughout her undergraduate education at Chatham University. In the summer of 2005, she volunteered in the access technology center at Blind and Vision Rehabilitation Services of Pittsburgh. She completed her master's from the University of Pittsburgh in Rehabilitation Counseling. She is currently working for Blind and Visual Rehabilitation Services.

Rachel Reimert

Age- 19

Disability- Learning Disabilities

Location- Kempton, PA

Activities- Rachel is currently a college student, pursuing a degree in education. In addition to being involved with the PYLN, Rachael has been involved in chorus, Credo, and drama club at school. She was a back stage helper/manager of a school play. She has received the "X" Award, Aspiring Student Award, and has been a peer tutor, and a High Honor Roll student.

William Schoy

Age- 17

Disability- Hard of Hearing

Location- McKeesport, PA

Activities- Bill became a member of PYLN in 2008. He is a student at McKeesport Area High School where he participates in Track and Field and takes courses in preparation for college. In addition to his efforts with the PYLN, Bill participates on the DePaul School for Hearing and Speech Gala and Alumni Fund-Raising Committees. This summer he is also working for Project H.E.A.R.T., an HIV/AIDS Education and Research Training Collaborative based in McKeesport. With the onset of football season this fall, he will continue his work as a High School Sideline Shooter/Videographer for Channel 11 news.

Gillian Withey

Age- 24

Disability- Epilepsy /Uncontrolled Seizure Disorder

Location- Pittsburgh, PA

Activities - Gillian is new to the PYLN Governing Board this year. In addition to being involved in the PYLN, she participates in a symphony in her community and plays the trumpet. She is still looking for employment, but graduated from Edinboro University of Pennsylvania in 2008, majoring in social science with an emphasis in statistics and research. She minored in music as well, being part of the school bands. Hobbies of hers include cross-stitch sewing and making thread bracelets. It makes her feel good being part of the PYLN and she plans to continue to be part of it.

PYLN Adult Allies

Adult allies support the work of the PYLN and follow the leadership and vision of its members.

Michael Stoehr

Title- Educational Consultant
Employer- The Pennsylvania Training and Technical Assistance Network (PaTTAN)
Location- Pittsburgh, PA

Joan Kester

Title- Senior Research Associate
Employer- The George Washington University, Center for Rehabilitation Counseling Research & Education
Location- Mount Joy, PA (Lancaster)

Linda Loar

Title- Parent Advocate
Employer- Parent Education Network
Location- Pittsburgh, PA

Joan Badger

Title- Family to Family Health Information Coordinator
Employer- Parent Education Advocacy Leadership Center
Location- Wampum, PA

Marty Kester

Title- Disability Advocate
Employer- Retired Bureau Director, PA Office of Vocational Rehabilitation
Location- Mount Joy, PA (Lancaster)

Sally Jo Snyder

Title- Community Organizer
Employer- Consumer Health Coalition
Location- Pittsburgh, PA

Sharon Gretz

Title- Executive Director
Employer- Childhood Apraxia of Speech Association of North America
Location- Pittsburgh, PA

FRIENDSHIPS AND RELATIONSHIPS

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Family Involvement

Family Involvement: Bond's Story

Hello, my name is Bond. I have Asperger's Syndrome, I am 18-years-old and will enter my senior year of high school this fall. I come from a very close knit family that has always been very supportive of me. I feel that a person's family is the strongest influential factor in one's life. I live with my brother, who is one year older than me, and also my mother. My mother has always been a strong advocate for my needs, both personally and academically. She has helped me find ways to deal with personal challenges, such as zoning out, being socially appropriate, controlling the volume and tone of my voice, etc. Academically she has made sure that my needs were always met both in IEP meetings and throughout the school year. Also, very importantly, she has always strongly supported and encouraged my advocacy for Asperger's Syndrome. Socially my brother Blaize has helped me a lot. He has a close group of good friends and over the years I too have become friends with them. I do have friends of my own, but I wouldn't consider those relationships to be as strong as the ones I've made with my brother's friends. I've also had much support from other members of my family such as my dad and his girlfriend (who both live in Chicago) and my grandmother. Just like my mother and brother, they too have always been supportive in helping me address my challenges and achieve my goals.

Family Involvement

Introduction

Family involvement is the way members of your family participate in your life. This is especially important when you have a disability, because your family is the closest support system you could have. They can help you learn more about your disability by helping you research information about it and find tips on how to get through life with it. They should be there for you when times are rough and you need guidance. They are the ones who love and understand you the most.

Support vs. Control

While it is important that your family gives you support and guidance, it is also important to understand the difference between support and control.

Support is when your family cooperates with you to help make important decisions about your life and encourages you to learn how to be as independent as possible.

Control is when your family makes decisions on your behalf. These decisions may be made without your input, or they may make you feel uncomfortable.

Here are examples of both:

- Support: Your family helps you plan what you want to do after you graduate high school (ie. Going to college, assisting with options concerning independent living).
- Control: Your family wants to have you placed in assisted living after high school without discussing it with you because they think you can't handle being independent.

Emotional Support

One of the most important things a family can provide is emotional support. Studies have shown that negative behavior in students is often linked to a low level of family involvement. This is often because the student feels frustrated and

thinks there isn't anyone he/she can turn to for support. This type of support includes:

- Comfort
- Encouragement
- Patience

Your family can also help you learn how to appropriately deal with:

- Frustration
- Anger
- Disappointment
- Sadness
- Anxiety
- Fear

Ways Your Parents Can Help You

Your parents are the ones who can provide the most support. Depending on your age group, the types of support they can provide vary:

Youth:

- Organize movie nights with your friends at your home or the theater.
- Drive you and your friends to social gatherings (such as parties, school dances or any kind of meeting that encourages networking between individuals with similar disabilities).
- Give you reminders to stay in touch with your friends via emails and/or phone calls.
- Assist with homework as needed, meeting with teachers to review progress or concerns, etc. to promote academic success.

Transitioning Youth:

- Look at colleges and vocational schools with you.
- Help you learn to navigate public transportation, learn how to drive, or find any other methods of transportation.
- Assist in the research of independent living options.
- Have discussions with you concerning course selection in both secondary and post-secondary education.

Sibling and Extended Family Support

Your parents aren't the only members of your family who can provide support. Siblings (brothers and sisters) or extended family are another source of support. Siblings can help provide socialization opportunities by including you in their activities with their friends. They can also be resources in helping you learn about your questions and concerns about navigating life in general. In addition, grandparents (if they live close by) can be very important to your health and well-being because they are often retired and have more free time.

Family Involvement: Do's and Don'ts

Do:

- Research your disability with your family to gain a better understanding of it. Some ways include:
    - Online research
    - Reading books about your disability
    - Networking with others who have had experiences with your disability
    - Looking for resources in your community, such as family support groups and/or sibling support groups. Studies have shown that external support can lead to more family participation in a youth's life.
- Learn how to be patient and tolerant of each other.

- Acknowledge and embrace your disability and find ways to navigate the challenges that go along with it.
- Take opportunities to learn how to be independent while you're still living with your family. This will make the transition to independent living easier.
- Find ways to navigate your surroundings (ie. wheelchair accessibility, guide dog, etc.).
- Maintain open lines of communication between family members.
- Be informed, respectful and cooperative with the school staff when discussing one's IEP.

Don't:

- Assume you're less important than anyone in your family due to your disability.
- Allow your disability to get in the way of family togetherness.
- Reject support from your family.
- Be afraid to ask for help from your family when needed.

Conclusion

Active family involvement is the most influential factor in a youth's development. Studies have shown that family involvement leads to increased academic success through better grades and test scores, a more positive attitude about life, and more ambitions for one's self. Studies have also shown that family involvement has a positive effect on a youth's life regardless of ethnicity or the family members' levels of education.

Peer Pressure

Peer Pressure: Bill's Story

Hi, I'm Bill, I am hard-of-hearing and I am going to be a sophomore in high school. This year, I've worked hard in school and made good grades. I started all of my assignments ahead of time and made sure I tapped all of the resources I needed to access information. My hearing support teacher and my interpreter have been extremely helpful. I began to encounter some problems in January when a couple of other students started to pressure me to do their homework for them. They even offered to pay me to write papers for them and complete their worksheets. I didn't feel comfortable telling my teachers-that would be snitching and would make more trouble for me with my peers.

I talked to my mom and older sister and her boyfriend. We discussed the problem over dinner. Talking really helped, especially with my sister and her boyfriend because they are only a few years older than me. They helped me understand that if I did homework for other people, it was not only dishonest but would "open the door" for me to be used again. I would be known as a push-over.

I faced the bullies and told them to back off. After a week or two, they stopped pressuring me.

Peer Pressure

Everyone experiences peer pressure: children, teens, and adults; It is a normal part of social interaction. Peer Pressure can be positive or negative.

- **Positive peer pressure** encourages helpful, goal-fulfilling behaviors. Responding to positive peer pressure benefits your family, society, and **YOU**. Positive forms of peer pressure can direct you to apply to college, look for a good job, or join an organization that helps others or our environment.

- **Negative peer pressure** on the other hand leads you to take part in bad behavior. Negative peer pressure can be obvious or hidden. It can influence you to do things that may cause problems for you and others. Giving in to negative peer pressure can lead you to drink, smoke, take illegal drugs, bully others or destroy property.

Can youth with disabilities be more influenced by negative peer pressure?

YES!

Youth with disabilities may feel different from other youth. They may feel left out or alone and may lower their values to try to fit into a group. Teen-agers and young adults, youth with disabilities can be taken advantage of and manipulated.

How can youth with disabilities deal with negative peer pressure?

- Take each day at a time
- Talk about your feelings and experiences with youth who care
- Learn to understand emotions and respect your self
- Think ahead to avoid problems; think before you act
- Avoid situations that can lead to trouble
- Speak up and get help when you need it; advocate for yourself
- Before making a decision, ask yourself:
  - What would my family think??
  - Would this go against my values??
  - What would the consequences be??
  - Is it worth it??
  - How would this affect me??

How to Socialize and Meet New People: Bond's View

Socialization is a term used to describe casual interactions between people. Most people already know or have been shown how to socialize, but for some this ability doesn't come as easily. Some people have problems with reading body language, facial expressions, tone of voice, making friends and/or knowing what is or isn't appropriate in social settings. This section will help you learn about all of these.

Body language and facial expressions are very important forms of non-verbal communication. They can effectively display one's emotions and/or what one might be thinking. For example: if a person was smiling, he/she would most likely be in a happy mood. If a person was frowning or had his/her head down he/she would most likely be feeling sad or upset. You can use body language and facial expression to gauge a person's mood and determine how to approach him or her.

Tone of voice is also a good indicator of how one might be feeling. If a person's voice was loud while telling you what you should do, he/she would be being demanding. If a person's voice is soft and/or quiet he/she might be feeling shy or not in the mood for talking. Tone of voice is also a good indicator of how one might be feeling.

You can also use body language, facial expression, and tone of voice as you communicate. Being aware of your expressions and tone of voice can help you get your ideas and feelings across. You can also avoid expressions or tones that could negatively affect how people interpret your interaction with them.

Making friends is difficult for those who aren't very good at socializing. When meeting new people, it's difficult to start a conversation with them because you don't know what they like to talk about. Common topics you can bring up to help break the ice include music, current events, movies, the weather, etc. (avoid bringing up controversial topics) . If you find that you have something in common, take the conversation from there. If you can't, the other person might not be interested in talking and you should politely leave the conversation and look for someone else you could talk with. When the conversation is over, tell the person you were talking to that you enjoyed your time with them and hope to keep in touch if you're getting along well with him/her.

Chaz & Allison on Relationship Building

Relationship building is something that we learn throughout our lives and is something we get better at as we develop. It can be a key part in transitioning at any point in life. It is critical to develop a group of local and community contacts to be able to provide you a source of information. It is important to be able to reach out to someone and they can guide you to the source of information you need. Relationship building gets easier with time as we start to learn more do's and don'ts of socializing and networking.

Here are some DOs and DON'Ts to get you started:

DO:

- LISTEN – be attentive and focused when listening to others
- Pay close attention to body language when having in-person meetings.
- Use your friends as an information source.
- Keep all your phone numbers in an accessible place.
- If you keep an electronic device to store contact information, be sure you back-up your lists (such as phone numbers and addresses) in another location.

DON'T:

- Discuss controversial topics such as religion and politics when you first meet someone.

Tips

- Follow-up with your community contacts on a regular basis.
- Have a purpose when contacting folks – an objective you want to complete.
- People are all around you to help you…don't be afraid to ask!
- Finally – BELIEVE IN YOURSELF!

Mentors

A Mentor is someone that you can trust as a counselor or guide to assist you with career planning, program planning, and overall support. This person is someone to use as an adviser, supporter, and sometimes friend. This person is usually older and always more experienced. It is there to help and guide in overall development.

- Where to get a Mentor (some sites to get you started)
  - www.pa-ementor.org/contact.shtml
  - www.mentoring.org/

- How a Mentor can help – a Mentor can guide you along your chosen career path. They can be a valuable source of information as most often they have already been through many of the things you are dealing with currently. Trust them!!!

Sexual Assault/Predators

Allison on Sexual Assault/Predators

Definition

Sexual assault is any unwanted physical or sexual contact. This can include unwanted touching and/or sex.

Statistics

-Between 40-90% of females with disabilities are raped
-3-10% of rapes are reported
-Only 5% receive counseling

What to do if you are a victim of sexual assault

If you feel that you have been sexually assaulted, the first and most important step is to tell someone that you trust. Don't be afraid. You have been abused, and abuse should never go unreported. The person you tell will most likely encourage you to call the police. If you're by yourself and don't have a trusted person around to talk to, call the police yourself. If you suspect that you might be pregnant or may have contracted an STD (sexually transmitted disease) as a result of sexual assault, it is extremely important that you see a doctor. In fact, seeing a doctor right away could help to catch the assaulter, because DNA samples can be collected during the examination.

Seeking additional help

While it is certainly important to ensure your physical safety following sexual assault, it is just as important to make sure that you heal mentally as well. It is probably a good idea to seek counseling. Many insurance companies will cover counseling sessions, but there is usually a free counseling center in most local

communities. There are also specific national and local organizations which deal with recovery from sexual assault. They often provide individual and group counseling as well. Examples of some agencies include Pittsburgh Action Against Rape, and The Center for Victims of Violence and Crime.

Preventing sexual assault through internet safety

It's very common for people to meet over the internet. However, there can be definite safety risks. It's important to be very careful when talking to people over the internet, because while many people are who they say they are, many others lie about their identity. Here are some general internet safety tips to follow.

1. Never give out personal information such as your last name, address, or phone number in a chat room, or on a site like MySpace. You can also set your account as private so that only certain people can contact you.
2. If you feel that someone is chatting to you in a threatening or openly sexual way, block him or her immediately.
3. Always be cautious of adults who try to chat with you. Obviously, there are many good adults out there, but many sexual assault crimes that begin with online chatting are adults preying on youth.
4. If you do make a friend your own age and want to meet with them, decide on a public location, and take trusted friends with you.

Individual Interests and Community

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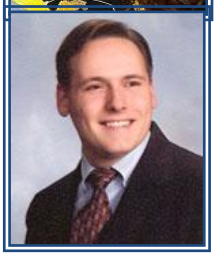
Hobbies and Interests

Rachel and Jeff on Hobbies and Interests



Hobbies and interests are activities or things that you enjoy doing and find fun. It is something special that should be important to you. There are so many hobbies/interests in the world, so finding the right one for you can be hard to do. When you do find the right hobby/interest, it can help you in many parts of your life. Once you find something that makes you happy and you find interesting, it could grow into something more like a job or career.

Here are some questions to help you think about different hobbies and interests:

1. What does hobby/ interest mean to you?

_____

_____

_____

2. Do you like working outside?

Often	Rarely	Never

What do you like to do outside?

_____

_____

_____

3. Do you like working indoors?

Often	Rarely	Never

What do you like to do indoors?

_____

_____

_____

4. Do you collect anything?

Yes	No

What do you collect?

_____

_____

_____

5. Do you like to play or watch sports?

Yes	No	Sometimes

What kind of sports do you like?

_____

_____

_____

6. Do you like to build or plant things?

Yes	No	Sometimes

What do you like to build or plant?

_____

_____

_____

7. Do you like to do arts and crafts?

Yes	No	Sometimes

What kind of arts and crafts:

_____

_____

_____

8. Do you like to travel?

Yes	No

Where would you travel to?

_____

_____

_____

9. Do you like working with or helping people, animals, or being alone? Circle all that apply:

People	Animals	Alone

What kind of work do you like to do?

_____

_____

_____

10. Do you like learning new things?

Yes	No	Sometimes

If so what is it:

_____

_____

_____

11. What do you like to do for fun?

_____

_____

After finishing this worksheet, you should have some ideas of what your interests are. For example, if you put down that you like working with animals, volunteering at an Animal Shelter may be the hobby for you. To find a hobby that is a good fit, it is important to think about your interest first, and pick something that relates to it. If you need help finding the right fit ask a friend, teacher, or professional. If you find a hobby you like, and have opportunities to experience and practice the hobby, it could lead to an exciting career. Whether or not your hobby becomes a career, it is important to do things you enjoy in order to live a balanced life.

Joe and Rachel's Ideas on Community

There are many ways to get involved in your community, including accessing your neighborhood resources, participating in events and activities, and volunteering.

First, it is important to figure out what your interests are, and what kinds of things you can do in your community. These could include organizations such as the YMCA, youth groups, church groups, recreational facilities, libraries, theaters, or sports facilities. Look for those that offer activities and programs around your interests.

Next, consider what you will need in order to participate in these activities or facilities. Examples include transportation, funding, and any accommodations that you might need.

Another way to access your community is to volunteer. Using websites, research what organizations in your community offer volunteering opportunities. These could include hospitals, personal care homes, or foundations such as MDA or Autism Speaks. Then contact the organizations or foundations and ask for information, or possibly set up a meeting with the volunteer coordinator.

Community involvement brings out the best in people and shows that they care.

Arts, Music, Drama

Kelly and the Arts

My name is Kelly and for most of my life I have been expressing myself artistically. My passions continued throughout college, where I studied in theater, music, and philosophy. Nowadays, I sing and play the piano, bass guitar, and drums in a band. I also have performed in over 25 theatrical productions. Expressing myself through art gives me an outlet to express what sometimes words cannot explain. I've also found strengths within my disabilities through the Arts. Performing on stage, many of my talents are actually helped by my symptoms; for example, my excessive energy helps me be a better performer whether I am singing, playing an instrument, or acting on stage. I believe that even my anxiety disorder has helped me become more aware of my emotions and "presence", which can be very beneficial for an actor. All of the Arts have allowed my always-active mind to explore while remaining relatively grounded. I believe that everyone should attempt to create; to realize this rewarding experience, but also to attempt to connect to others through art.

Disability and the Arts

It seems like all too often our lives are so full of stress and "business" that we don't have a way of releasing all of the tension and exploring that "other side" of our brain. For people with disabilities, it can be especially difficult-- for a variety of reasons-- to express ourselves. The Arts are a perfect venue for exploring self-expression and creativity. So, what do we mean by "The Arts"? In this context, we are referring to various types of self-expression, such as music, drama, dance, and also fine arts like painting and photography. Learning to express yourself artistically might not be easy for everyone, but remember, it's more about the process than the result.

People with disabilities historically have a big connection with the Arts. An obvious example would be a musician like Ray Charles, who expresses himself musically and is blind. But it is astounding to see how many actors, musicians, artists, and comedians, to mention a few, have invisible disabilities such as A.D.D or

Bi-Polar Disorder. Perhaps it is a certain way of thinking that is related to these types of disabilities that makes us creative, but there is definitely seems to be a correlation. The success of many of these artists should be an example of how beneficial some disabilities are in connection with the Arts.

Certain people with disabilities often have a high level of self-understanding and awareness, which is one of the keys to self-expression. Self- expression is a truly therapeutic aspect of life, and is one I believe everyone should posses in some regard. So perhaps take some time after reading this and research some areas that you could get involved in the Arts; whether through your school or community, there are several resources out there for you (the website www.vsarts.org is a great place to start)! And if you ever feel discouraged, www.disabled-world.com has a great section of Famous People with Disabilties that should show you that you are not alone!

Community Based Services

As you transition from school to the rest of your life, you will no longer have the support you receive from teachers, transition coordinators and school. Help is out there! You might want someone to help you with finding a job, going to school and living on your own. Here's a list of organizations that you can contact:

The Department of Health is an organization that provides information about health care and health care related services. This organization is run by the United States government. Some of the topics they deal with are:

- Preventing disease, including immunization services
- Assuring food and drug safety
- Health information technology
- Improving maternal and infant health
- Faith-based and community initiatives
- Substance abuse treatment and prevention
- Medical preparedness for emergencies
    - **Department of Heath**
        - Website: http://www.dsf.health.state.pa.us/health/site/default.asp
        - Toll Free: 1-877-724-3258

The Department of Public Welfare's mission is:

- Promote, improve and sustain the quality of family life;
- Break the cycle of dependency;
- Promote respect for employees;
- Protect and serve Pennsylvania's most vulnerable citizens; and
- Manage our resources effectively.
- Programs operated by the Department of Public Welfare include Medicaid medical benefits and services for individuals and families with disabilities
- Many of the programs are operated at the county level, so check the blue pages of your phone book

    - **Department of Public Welfare**
        - Website: http://www.dpw.state.pa.us/
        - Phone #: (717) 787-4592

Office of Vocational Rehabilitation:

OVR's mission is: To assist Pennsylvanians with disabilities to secure and maintain employment and independence.

- **Office of Vocational Rehabilitation (OVR)**
  - Website: www.dli.state.pa.us then click disability services
  - Phone #: 1-800-442-6351
  - TTY: (866) 830-7327

Centers for Independent Living (CIL)-- affiliated with the National Council on Independent Living (NCIL) whose mission is to:

Advance independent living and the rights of people with disabilities through consumer-driven advocacy. NCIL envisions a world in which people with disabilities are valued equally and participate fully. Centers for Independent Living (CILs) are managed and staff by a majority of people with disabilities and provide independent living skills training, information and referral, peer counseling and advocacy.

- **Centers of Independent Living**
  - Website: http://www.ncil.org/index.html
  - Phone #:
    - Voice: (202) 207-0334
    - TTY: (202) 207-0340
- **To find a CIL in your area, visit: http://www.pcil.net/**

Office of Developmental Programs (ODP) Mission:

Our mission is to provide individuals with mental retardation, autism, and their families the services and supports they need and the opportunity to make real choices about living, working and options for social activities to enable them to live in and participate fully in the life of their communities. The services are provided through the county MH/MR office.

ODP Services

- Website: http://www.dpw.state.pa.us/About/ODP/
- Central: (717) 705-8396
- Northeast: (570) 963-4335
- Southeast: (610) 313-5844
- Western: (412) 565-5226

Office of Mental Health & Substance Abuse Services (OMHSAS) Mission and Vision:

Every person with serious mental illness and/or addictive disease, and every child and adolescent who abuses substances and/or has a serious emotional disturbance will have the opportunity for growth, recovery and inclusion in their community, have access to services and supports of their choice and enjoy a quality of life that includes family and friends.

OMHSAS Goals:

- Transform the children's behavioral health system to a system that is family driven and youth guided.
- Implement services and policies to support recovery and resiliency in the adult behavioral health system.
- Assure that behavioral health services and supports recognize and accommodate the unique needs of older adults.

- **Mental Health Services**
  - Website: www.dpw.state.pa.us/About/OMHSAS
  - Regional Phone #:
    - Central: (717) 705-8396
    - Northeast: (570) 963-4335
    - Southeast: (610) 313-5844
    - Western: (412) 565-5226

PA Workforce Development/CareerLinks

From this website portal you will be able to access a number of online resources that will provide information on conducting a job search, Unemployment Compensation, disability services, labor market information, the Trade Act program, training and education, Veterans benefits, grants and financial aid.
https://www.cwds.state.pa.us/cwdsonline/Admin/ViewHomePage/PublicHomePage.aspx

Social Security

- The Social Security Administration (SSA) manages programs like SSI, SSDI, work incentives and benefits planning to help you plan for work, even if you're on SSI.
    - The Supplemental Security Income (SSI) program pays benefits to disabled adults and children who have limited income and resources.
    - The Social Security disability insurance program (sometimes referred to as SSDI) pays benefits to you and certain family members if you worked long enough and paid Social Security taxes.

- **Social Security Administration (SSA)**
    - Website: www.socialsecurity.gov
    - Phone #: 1 (800) 722-1213
    - Benefits planning list for PA: www.dpw.state.pa.us/Resources/.../Pdf/Fall2005BPAODirectory.pdf

BALANCE

Developed by youth for youth

1st Edition
July 2009
PYLN

Balance and Dealing with Stress

Balance and Dealing with Stress: Rachel's Story

Hi, my name is Rachel Kallem and I have Bipolar Disorder. I was diagnosed when I was 17 years old and while it has been a struggle, I have learned how to cope. Having Bipolar Disorder means I don't just have ups and downs, but I have manic episodes and depressive episodes. When I'm manic I don't need a lot of sleep and I have a ton of energy, I'm impulsive – which means sometimes I make bad decisions, and I can even become paranoid. When I have a depressive episode I feel hopeless and helpless – I don't take joy in anything and I just want to be alone. Having Bipolar Disorder is a challenge, but I've learned how to manage it. By living a balanced life I can better control my disorder. Triggers that can lead to cycling (having an episode) are not sleeping enough and when I don't take care of myself. If I eat right, exercise, and get enough sleep I have fewer episodes and I feel better. Through taking care of myself I can manage my disorder and be happier. It's simple steps like going to bed at a reasonable hour and making sure I go to the gym that really make the difference for me and help improve my quality of life. Even if you don't have a psychiatric disability it is important to take care of yourself and live a balanced life – it can make anyone feel better and be happier! You are responsible for taking care of you, so take it seriously and take care of yourself – you deserve to be happy!

Rachel's Suggestions for Dealing with Stress

Everyone deals with stress – stress is a normal part of life! But learning how to cope is key. While all people experience stress, for some, stress has more severe consequences like leading to anxiety/panic attacks or manic episodes.

Stress can be devastating for me because when I am really stressed out it can trigger a manic episode. Thus, I have to be careful and manage stressful situations so they do not result in a manic and depressive episode. A good way to manage stress is identifying your triggers. Some common triggers that can cause stress are:

- School work/job pressure
- Social situations/family situations
- Phobias – which are severe fears (like the fear of flying)
- Sensory overload – which means being overwhelmed by too many distractions

For me, school work and job pressure can be overwhelming and stressful. If I have a big assignment due, I find myself getting really stressed and worried about being able to complete the project.

Stress is normal since life is made up of some stressful situations, so what is important is learning how to cope with stress. Stress can't always be avoided, so learning how to manage your stress is critical!

Here are some strategies people use to cope with stress. See which ones work for you:

- Listening to music
- Exercising/taking a walk/doing yoga
- Talking with a friend/family member/therapist
- Taking prescribed medication
- Hobbies
- Relaxing techniques – like taking a bubble bath
- Spiritual outlets, like going to your place of worship
- Physical contact – like getting a hug from a friend or family member

It is important to find a coping style or coping techniques that work for you. For me, if I get stressed out I like talking with a friend or family member and listening to music. But, I also take medication to help me reduce stress. Medication allows me to calm down and cope better with stressful situations.

Choosing a healthy lifestyle is also essential. Eating well, exercising, and getting enough sleep is really important and will help you manage your stress much better. For me, if I eat a healthy diet, exercise regularly, and sleep enough I am more likely to handle stressful situations better and better yet, things are less likely to stress me out. By pairing a healthy lifestyle with coping techniques (like listening to music) I can live happily and handle my stress much better!

Stress is unavoidable in reality, but recognizing toxic situations can help you avoid some stressful environments. A toxic situation is a scenario in which you set yourself up for disaster by making bad choices. For example, I know if I take a full course load in school I am more likely to get overwhelmed by all the work. Thus, I take a reduced course load (fewer classes) and therefore avoid a toxic situation which might lead to a manic episode. Recognizing a toxic situation is really helpful in avoiding stress. Another example of a toxic situation is if I do not take my medication. I am definitely more likely to be stressed if I skip my medications, so I avoid that scenario all together by taking my medications as prescribed by my doctor.

So remember:

- Know how stress affects you! What happens when you are stressed out and what can you do to cope?
- Identify your triggers! What things are likely to make you experience stress?
- Pick coping techniques! What coping techniques work well for you to help you feel less stressed out?
- Live a healthy life style! Make sure to eat right, sleep enough, and exercise because a balance life is a balanced approach to managing stress.
- Avoid toxic situations! By avoiding toxic situations you are more likely to be successful.

Time Management

Bond on Time Management

Time management is the development of strategies used to efficiently maximize the use of one's time. It is a very important form of organization. When making schedules, routines or plans, one of the best ways to manage your time is to form an outline that will help you determine what you need to do and when to do it.

Here are some tips which may help you with this:

- Prioritize (What needs to be done the soonest?)
- Assess how long it will take to complete each task.
- Incorporate a reasonable amount of free-time into your schedule to avoid any potential stress.
- Know what other people are planning in order to avoid conflicts in schedule. (For example, if two of your friends were having birthday parties on the same day you couldn't plan on going to both of them. You would need to choose which one to go to.)
- Be aware and respectful of the possibility that the plans of others may not fit into your plans.
- Make sure the plans you are making are realistic based on the time you have available.
- Keep in mind what time of the day you are most productive when fitting work in.
- Use a watch or a cell phone clock to help you keep track of the time.

Even though it is important to stick to a schedule it is also important to be flexible in case things don't go as planned. If you invited someone to your house at 4:00 p.m., and he gave you a call at 3:55 p.m. to tell you he would be a half-hour late, it would be best to accept the fact and modify your plans. Personally, I have some trouble with being flexible when the time calls for it because I'm too

concerned with punctuality (I believe this is probably due to my Asperger's Syndrome). For example, if I had a guest over who said he would stay until 7:00 p.m. and the clock reads 6:58 p.m. I would inform the person of the time and try to help him get ready to leave in a way that might accidentally imply that I was trying to kick him out. When trying to keep or make a schedule, one must consider the feelings, needs, and plans of the people around him/her.

If you have homework to do, a book to read and/or a school project to complete, it is best to split the work up into sections (or chapters in the case of books). For example: if there's a project that seems to require much work and is due in two weeks it's possible to do a single part of it each day if you get an early start on it. With a book, you could just read a chapter or a certain number of pages each day. The *worst* way to handle a project is to procrastinate. Putting it off until the last minute will force you to do the whole project at once, and this causes a huge amount of unnecessary stress. It could even cause you to forget you ever had a project to do and, if it was a school assignment, you would get a failing grade for not turning it in.

Living a Balanced Life

Kate on Living a Balanced Life

Part of everyday life includes completing all of your activities and responsibilities in your day, but sometimes it may seem that 24 hours in a day just is not enough! However, living a balanced life means getting done what needs to get done, having some leisure time for yourself, and of course, catching those very important zzz's.

Activity Time Management: How a Normal Day Flows

Worksheet: Mapping out your daily schedule to squeeze in you, your disability, and pretty much everything in between!

The PYLN knows having a disability can sometimes add more responsibilities to your day.

Filling out your *ideal* schedule below can give you insight into how you would like to spend your 24 hours each day.

Remember to include sleeping, eating, and other activities you want to get done during your ideal schedule.

Ideal Schedule

12am-1am

1am-2am

2am-3am

3am-4am

4am-5am

5am-6am

6am-7am

7am-8am

8am-9am

9am-10am

10am-11am

11am-Noon

Noon-1pm

1pm-2pm

2pm-3pm

4pm-5pm

5pm-6pm

6pm-7pm

7pm-8pm

8pm-9pm

9pm-10pm

10pm-11pm

11pm-Midnight

Now choose a typical day and fill out your *ACTUAL* schedule below.

12am-1am

1am-2am

2am-3am

3am-4am

4am-5am

5am-6am

6am-7am

7am-8am

8am-9am

9am-10am

10am-11am

11am-Noon

Noon-1pm

1pm-2pm

2pm-3pm

4pm-5pm

5pm-6pm

6pm-7pm

7pm-8pm

8pm-9pm

9pm-10pm

10pm-11pm

11pm-Midnight

Follow-Up Questions:

1. How does your *actual* daily schedule compare to what your *ideal* schedule looks like (ex: are you sleeping more/less in your actual schedule)?

2. Why do these differences exist? Were there any differences that surprised you?

3. How can you change your actual schedule to look more like your ideal schedule (ex: should you be doing your school work earlier so you can get more sleep)?

Procrastination

When you put off your work until the night before it is due or an activity that needs to be done by a certain date, your entire schedule can be affected. Maybe you will not get to watch your favorite TV show or maybe you will not get to "shop till you drop" with your friends because you procrastinated. So how do you have your cake and eat it too? Well, here's how:

Helpful tips to Stop Procrastinating:

- Work ahead and plan accordingly.
- Break up jobs or assignments into smaller, more manageable parts.
- Set deadlines and make priorities.
- Use a calendar or planner to keep track of all your assignments, deadlines, and progress.
- Complete your work in a non-distracting environment to stay focused.
- Think about your ideal schedule and what you want to get done; set goals for yourself!

Rest

Sleep - Living a balanced life certainly includes sleep!

Chaz on Rest

Activity

Calculating Your ZZZ's

Worksheet: You may have never sat down and taken a hard look at your sleeping habits, but those precious hours can definitely help get you on the path towards living a balanced life.

1. How many hours a night do you actually sleep?

2. How many hours a night do you think you should be sleeping?

3. What can you do before bed to get a good night's rest? Do you read, listen to music, etc.?

For a balanced life, it is suggested by professionals that every person gets eight hours of sound sleep per night to be at their best. Be sure to relax before turning out the light because worrying about deadlines, exams, and other stressors can prevent someone from falling asleep or sleeping throughout the night. Without a proper amount of sleep, your body will not be able to recharge; you may not be alert or have enough energy to take on the next day's busy schedule.

Tips for a Good Night's Rest:

- Avoid long naps or naps in general.
- Minimize noise and light in your room.
- Stay away from caffeine before bedtime.
- Stick to light snacks close to bedtime—no heavy meals!
- Relax and unwind before sleeping.

A Balanced Life Takes Work!

Keep in mind all that goes into living a balanced life, such as creating a schedule (and sticking to it!), working ahead and not procrastinating, and maintaining an adequate sleep routine. You live a very busy life, but it is important to remember all that goes into keeping yourself healthy and happy. A little bit of effort on your part can go a long way in creating and maintaining a balanced life!

Spirituality

Kelly and Her Faith

Spirituality is a topic that is not often discussed openly, even though it is a vital part of many people's lives. Recent polls have revealed that nearly 87% of Americans consider themselves religious, and 92% believe in God. Spirituality can sometimes be a subject people avoid for fear that they are infringing on other people's beliefs, but when faced with these statistics, it is obvious that many share a need for spirituality in their lives. Spirituality can be connected with an organized religion or a personal one, and involves finding meaning in this world and what it means to exist in it.

People with disabilities often struggle with understanding ourselves and our disabilities (which are often deeply connected with who we are as a person and how we view ourselves). We also tend to wonder how we fit into the rest of our culture, and the "big picture" of our world. In this search for meaning and purpose in our lives, many of us find spirituality to help us in answering the "big questions." In believing in a higher power, we find the hope and strength that can help us through some of the hardest times (and also some of the better times) of our lives. We also can realize that we do have a very special place in the "big picture" of our world, and perhaps can teach others about life as well!

Being aware of my spirituality has been very beneficial in trying to make sense out of my Attention Deficit Disorder and General Anxiety Disorder. I have often been tempted to view my disabilities as a weakness in this world, but over the years I have come to realize that they sometimes can be blessings. I believe that God has given me creative talents that I have discovered are very common in people with A.D.D. My symptoms of both of my disability actually make me a stronger performer on stage. Of course there have been negative affects as well, but I have even learned and grown through my negative experiences with my faith and my disabilities. Part of making sense of my disability involved my faith in God. Because of my faith, I have more purpose, motivation, and connection to others in my life.

Even if you don't believe in a higher power, you can believe in your inner spirit, which has benefits like self- empowerment and motivation. Many people who believe in themselves also believe in a higher power, which can give them strength. A way to feel connected with yourself and/ or a higher power is to practice meditation—such as yoga and prayer. Both of these activities involve a quiet time of reflection, apart from others, and can make you more relaxed and focused. Any way you view your spirituality, it is often a very healthy and therapeutic practice. So next time you are talking with a friend, family member, or even a counselor, don't feel afraid to bring up the subject of spirituality-- it's a natural and beneficial part of life!

My Leap of Faith- Josie

"I thank God for my handicaps, for, through them, I have found myself, my work, and my God."

-- Helen Keller

This quote by Helen Keller sums up a lot about how I have come to accept my disability and faith. For me, disability and faith have a symbiotic relationship. I grew up in a Christian home and have had my disability since birth so these were always normal parts of life. However, it was not until I truly accepted my disability and grew in my faith that I began to understand myself and my role in the world. Once I started viewing my faith with an acceptance of my disability I was able to see the true role of disability in creation. Disability is not an accident, it happens for a reason and people need to treat it with dignity and respect. Life, especially with a disability, is often out of our control. My faith helped me in managing these situations and being able to handle whatever comes my way. My faith helped me to accept my disability and find pride in who I am as a creation that was purposefully made. My disability is not a mark of an erroneous state, but rather it is a symbol of my unique identity. If I had the opportunity to be medically cured I would refuse because I would no longer be who I was meant to be. I would lose my identity and purpose in life. I feel that I am meant to spread disability awareness and to speak for the people who cannot speak for themselves.

Accessible Faith Communities

Allison's Story on Faith Communities

Spiritual health is just as important as physical and mental health. Therefore, it's important for many people to find a faith community in which they can fully participate and feel accepted. I am fortunate in that I was always accepted in my faith community. I grew up attending a Catholic church near my home. When I was seven, I decided to join the children's choir. The director was very accommodating, and recorded the songs for me so that I could learn them by ear. As my vocal talent developed, I was given various opportunities to sing solos. I always felt respected by the other members of my church, and I don't feel that anyone thought less of me because of my disability.

Barriers to Inclusion in Faith Communities

Barriers often exist in the form of stigma caused by negative attitudes of people without disabilities towards people with disabilities. Some people also mistakenly believe that disability is a form of punishment from God, and therefore do not want people with disabilities to be a part of their faith community. Others simply are not educated about the things that they can do to help people with disabilities to feel included. These are the people that one might be able to reach most easily.

Another major barrier to inclusion in faith communities exists in the form of inaccessibility of the actual buildings in which worship takes place. For example, in many churches, you must climb stairs in order to reach the sanctuary. This essentially isolates individuals in wheelchairs who may wish to worship at that particular church. The leaders at that church should be educated about options for making the church accessible, such as wheelchair ramps and stair lifts.

Participation in a faith community is a right which must be extended to individuals both with and without disabilities.

Ways to Ensure Inclusion

- Ask for the accommodations you need. Outreach and helping others is a form of ministry.
- Educate others about disabilities and accommodations.
- Volunteer for various activities in your church like spaghetti dinners, bingos, choir, etc.
- Whenever possible, try to take on a leadership role. For example, offer to lead a prayer.

DIET AND EXERCISE

Developed by youth for youth

1st Edition
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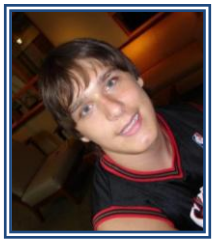
Diet and Healthy Eating



Lewis and Rachel on Diet and Healthy Eating

It is important to take care of yourself – and life on your own can pose some unique challenges to your health. For example, finding time to eat balanced meals while taking classes, doing homework, or working can be tough. It can also be hard to make healthy food choices because life on a budget means eating cheaper, which makes fast food more affordable. When people get busy, they are more likely to eat a quick fast food meal instead of a healthier one to save time. However, despite your busy schedule there is a lot of value to eating well, eating on a schedule, and avoiding unhealthy foods or only eating them in moderation (small amounts).

Stress can also make people gain weight. Some people will overeat when they are stressed out, and for most people life has some stressful moments. However, some people do the opposite when they are stressed and do not eat a lot of food, and this can be dangerous too. It is important to keep a healthy diet because you will be at your absolute best!

In addition to stress, your emotions can affect what you eat and thus impact your weight. When some people are anxious or depressed they will eat unhealthy foods which can lead to weight gain. However, some people are affected differently and if they are depressed they will not each very much which can lead to unhealthy weight loss. Some people may develop eating disorders, which is basically when you have trouble eating healthily. This can either mean you eat too much (binge eating disorder), or you do not eat enough (anorexia nervosa), or you eat and then purge (bulimia nervosa). For more information on eating disorders you can talk to a professional or check out the following website: http://www.nationaleatingdisorders.org/

Eating disorders are dangerous and can cause physical and emotional problems for people. If you suspect a friend has an eating disorder it is important to refer them to help right away. If you are worried that you may have an eating disorder please talk to a health care professional! Eating disorders are easier to recover from if an individual gets early treatment, so be sure to get help sooner than later.

Something to keep in mind: if you are on any psychiatric medications a related side effect can be weight gain or weight loss. It is important to know what side effects could affect you, so talk to your doctor about what to watch for. If your medications can lead to weight gain, be sure to exercise regularly to prevent becoming unhealthy. If your medications might lead to weight loss, monitor your food and make sure you are eating a balanced diet.

Dieting

America has become the most overweight country in the world. The United States has an obesity problem and it is mainly because of the availability of fast foods and the lack of physical activity. Hollywood has been no help; they show images of everyone being so thin. These images of thin people make everyone question what a normal weight really should be. The pressure to be thin has caused many of our young people to turn to dieting. Some young children see the people around them dieting and they start to think that they should be worried about their weight too. If a young person was to start dieting, they could experience some unexpected repercussions like eating disorders or they could develop a distorted body image of themselves. Everyone has become obsessed with dieting. Everywhere that you look, you see advertisements for diet programs. There is the Jenny Craig diet plan, the Weight Watchers diet plan, NutriSystem, and The Atkins diet to name a few. There is no magic to dieting. The one way to really lose weight is to eat fewer calories than you burn, it is just that simple.

A Proper Diet

One of the most important things for many people is their self image. Everyone wants to be comfortable in their own skin. If everyone ate properly and exercised several days a week, there would not be a need for dieting. If you do find that you need to lose a few pounds, there is a right way to lose the weight. To start a diet, you will need to learn what a balanced diet really is and you will need to learn about what is meant by a portion size. Eating a balanced diet means eating a wide variety of foods. A traditional way of getting a balanced diet has been to eat a certain number of portions from certain food groups. The five basic groups are vegetables; fruit; bread and cereal; dairy; and meat, poultry, fish, and legumes (dry beans, lentils and peas).

Everyday everyone should have four servings from the fruit and vegetable groups. From the bread and cereal groups, it is recommended that you have six servings, which include some whole-grain breads and cereals. The recommended servings from the milk and cheese group vary with age; the highest recommendations for these are for teenagers and for nursing mothers and they need at least four servings each day. Every day you should have two servings from the meat, poultry, fish or bean group.

Know your Portions

Portion sizes can be confusing. Use some of these comparisons to help you to understand what is meant by a portion size or a serving size. Add an updated food pyramid (visual)

- Vegetables and fruits should be about the size of your fist.
- A serving from the meat, fish, or poultry group should be the size of a deck of cards.
- Limit snacks like pretzels and chips to about the size of a cupped handful.
- A serving of pasta should be about the size of one scoop of ice cream.
- A potato should be about the size of your computer mouse.
- A piece of cheese should be the size of your thumb.

MyPyramid.gov
STEPS TO A HEALTHIER YOU

http://mypyramid.gov/

MyPyramid offers personalized eating plans and interactive tools to help you plan and assess your food choices based on the Dietary Guidelines for Americans.

Alcohol and Medications

Rachel on Alcohol and Medications

A normal part of getting older is meeting new people and making friends. This can take place in classes, clubs, work, or at parties. Sometimes social events with these new friends involve drinking alcohol. Some people choose to drink alcohol, but it is important to know that this is a CHOICE. If you are 21 and want to drink alcohol you can do so, but no one should pressure you into drinking. If you do choose to drink, it is important to do it safely.

There is a common stereotype that drinking is "normal" and everyone does it, but for many people drinking alcohol is not part of their every day experience. If you do however choose to drink it is important to remember that drinking in moderation (small amounts) is important. It is okay to drink a little bit of alcohol, but going over board is never a good idea and could be very dangerous. Many people have fun without drinking and it is important to know you can drink responsibly and still have a good time!

Remember:

Drinking a little can be considered normal behavior, there is nothing wrong with one drink if you are legally allowed to drink alcohol, but drinking to excess is **NOT** normal.

The dangers:

Drinking can be dangerous, and some people who start drinking alcohol experience problems. For example, some people start drinking when they are upset or angry as a way to escape their problems and this is very unhealthy. Sometimes, people will self-medicate with alcohol and this is very dangerous. Drinking never solves your problems, but it can create new ones!

Here are some warning signs that you might have a problem with alcohol:

- If you drink alone
- If you can only have fun after a few drinks
- If you pass out because you drink too much
- If you drink to escape your problems
- And if you "need" a drink to function

Having a disability and what it means in regards to drinking:

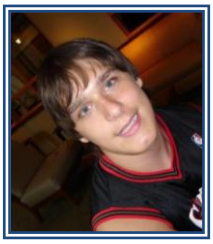
Having a disability can sometimes mean you have to be more careful with consuming alcohol. Don't try to keep up with your friends. Alcohol effects everyone differently with or without a disability! Both your gender and weight can affect how your body handles alcohol too, so it is important to know your limits and take it easy.

If you take medications, it is important to talk to your doctor and see if there are any negative interactions that can result if you drink while on your medications. Your safety is the number one priority, so make sure you communicate with your doctor and find out what is safe for you!

Another safety issue is making sure you watch your drink at all times if you are at a party or social event. Drinks can be "spiked," meaning drugs or more alcohol can be added to some's drink without his or her knowledge. This can be very dangerous, so be smart and always pour your own drink and hold onto your drink at all times. Remember you need to be 21 or older to legally drink!

Be safe, be healthy – drink responsibly or don't drink at all!

Sports and Exercise



Chaz and Lewis on Sports and Exercise

Maintaining Your Body

Physical activity is critical to maintaining a healthy mind and body. Working out does not mean you have to spend hours in the gym lifting a thousand pounds. Working out can mean doing anything that involves physical activity.

Exercise

Why is exercise important?

- Exercise keeps us active and overall healthy.
- Exercise is one of the best ways to control weight. Exercising will overall boost your metabolism which will assist in controlling your weight.
- Exercising regularly, builds strong muscles, gain stamina, and increase energy.

Workout information

- Before starting a new diet or exercise program, it is wise to check with your health care professional.
- Before any type of workout, make sure you stretch well to prevent injury.
- Always workout with a partner to be sure you do the exercises safely and properly.
- If you are new to working out, don't overexert yourself.
- If you're working out with someone else that is a workout veteran, don't under any circumstances, try to keep up with them. Go at your own pace.

More Tips for Exercising:
http://www.walgreens.com/library/contents.html?docid=000029&doctype=10

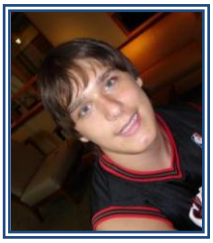
- Do not eat for 2 hours before vigorous exercise.
- Drink plenty of fluids before, during, and after a workout.
- Do warm-up exercises for 5 - 10 minutes at the beginning of an exercise session. Low-level aerobic exercise is the best warm-up.
- Adjust your activity level according to the weather, and reduce it when you are fatigued or ill.
- When exercising, listen to the body's warning symptoms.

Examples of Exercise:

- **Cardiovascular Workouts**
  - Pushing (propelling a wheelchair) a mile or a certain distance
  - Running on a treadmill
  - Going for a bike ride or using an arm bike
  - Playing any sport
  - Swimming

- **Sample Weight Workout**
  - 10- repetitions (Reps) of the bench press
  - 10 reps butterflies
  - 1 minute plank
  - 10 Dumb bell curls
  - 10 pull ups

The Role of Playing Wheelchair Sports in Lewis's Life



Playing wheelchair sports has had a profound effect on my life. I have had a disability since birth and unfortunately, I could not play conventional sports intended for the non-disabled. Ever since I could remember, I loved sports. I have always had a very competitive side and playing wheelchair sports has given me the chance to channel this. I play wheelchair basketball and wheelchair rugby.

Wheelchair basketball started 60 years ago when disabled veterans began returning home from World War II. Today, there are more than 200 basketball teams throughout the U.S. and Canada. Wheelchair basketball is the most popular wheelchair sport in North America. Playing wheelchair basketball has been a great way for me to meet other athletes and to make friends as I get to challenge my competitive side.

I started playing junior wheelchair basketball when I was 8 years old. I played for the Katie Kurlin's Basketball Team of Philadelphia. This team is made up of children 6 to 16. We traveled throughout the United States competing against other teams. By playing basketball, I finally had the chance to feel normal. Up until I started playing wheelchair basketball, I was never really around other people in wheelchairs; this opportunity gave me the chance to see that I was not alone.

Today, I play wheelchair basketball and wheelchair rugby at a semi-professional level. I play basketball for the Philadelphia 76'er Wheelchair Basketball Team and I play rugby for the Philadelphia Eagles Wheelchair Rugby Team. Both teams travel extensively as they compete for the national title.

I am very fortunate; playing wheelchair sports has provided me with many opportunities that I might not have had otherwise. I have had the chance to meet many other athletes like myself and a lot of famous ones too. Wheelchair sports have given me the chance to make new friends and even enjoy some healthy competition. I have had the opportunity to travel to places that I might not have ever got the chance to see. It has provided me with a fun way of staying in shape on a regular basis. I am thankful that I have had the chance to play wheelchair sports.

Adapted Sports and Recreation

Sports and recreation are very important to learn about and participate in throughout life. They not only can assist in a healthy lifestyle, but they also assist in the development of coordination, reaction, build stamina, and overall increase physical fitness. Being disabled does not mean you cannot be a competitive, healthy person. There are several sports that are available for people with disabilities such as:

- **Basketball** – a team sport in which two teams of five players each try to score points by putting the ball through the hoop (10 feet tall). The game is played with organized rules and is one of the most popular wheelchair sports known worldwide. There are over two hundred teams for all genders, ages, and disabilities. **Played by Manual Wheelchair Athletes**
    - Resource Site: www.nwba.org

Basketball Wheelchair

- **Goalball** – is a team sport played by blind athletes. Developed in 1946 for rehabilitation purposes of visually impaired World War II veterans. The International Blind Sports Federation is the governing body for the sports
  Played by Visually Impaired Athletes
    - Resource Sites: www.ibsa.es/ --- www.usaba.org

- **Wheelchair Rugby (Murderball)** – This is a full contact sport that is most often played on a volleyball court or basketball court. The game is played with a ball and points are scored by crossing the goal line with possession of the ball. The opposing team is defending that goal and the winner is determined by the team with the most points when time runs out. Quad

rugby is a sport for people with a disability in at least three limbs. It gives a chance to everyone with more severe disabilities to be competitive. **Played by Athletes with some dysfunction in all four limbs**

- Resource Sites: www.quadrugby.com --- www.iwrf.com

- **Wheelchair tennis**- this sport is played just like standup tennis with only one change is the rules; you may return the ball on the second bounce. It must bounce three times on the opponent's side to score a point.

  - Resource Sites: http://www.itftennis.com/wheelchair/

Tennis Chair

- **Table tennis-** is played just like normal table tennis except you will only compete against people with a similar disability.

  - Resource Sites: http://www.midy.com/~usatt/parapong/

- **Volleyball-** it is played sitting down with a shorter net and smaller teams. The scoring is the same as regulation volleyball.

  - Resource Sites: www.usavolleyball.org/

- **Wheelchair softball-** is played on any hard surface with fences of two hundred feet and ten players on each team. The rules are the same as a slow pitch softball team.

  - Resource Sites: http://www.wheelchairsoftball.org/index.htm

- **Ice Hockey** – played as team sport on ice and is known across the world as a fast paced and very physical sport. Six players are on the ice at one time and one remains as the goalie to protect the goal. Scoring is done by placing the puck into the net of the opposing team. **Played by Athletes with hearing impairments and physical disabilities**

    - Resource Sites: www.ahiha.org www.amateurpenguins.com/index.php?team_id=14398

-
- **Other resourceful sites available:**
    - **Wheelchair Softball - www.wheelchairsoftball.org/**
    - **Wheelchair Track & Field - www.wsusa.org**
    - **Paralympics Information - www.paralympic.org**
    - **Deaf Ski & Snowboard Association - www.usdssa.org**
    - **Deaf Team Handball - www.usadth.org**
    - **United States Assoc. of Blind Athletes - www.usaba.org**

Other Adapted Sports Equipment

Source: http://www.topendwheelchair.com

Hand cycles

Racing Chair

Colleges

There are several colleges around the country that offer some sort of adapted sports and recreation for students with disabilities. Here are a few to help with the search:

- Edinboro University of PA – www.eup.edu
- University of Illinois - www.disability.uiuc.edu/athletics
- Southwest State Minnesota - www.smsumustangs.com
- University of Arizona – www.drc.arizona.edu/athletics/index.html
- White Water Wisconsin University
- Wright State University – www.wright.edu/crec/programs/adaprec.html
- Penn State University - www.athletics.psu.edu/ability

HEALTH PRACTICES

Developed by youth for youth

1st Edition
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PYLN

Talking to Doctors

Rachel on Doc Talk!

Everyone has to go to the doctor, but some types of disabilities mean you have to see doctors more often. For example, if you have a psychiatric disability you often have to check in with your psychiatrist, a doctor who deals with mental health issues, to make sure your medications are on track. If you have a physical disability, it is important to see your doctor or specialist, someone who is an expert on your disability, to make sure that you are healthy. Everyone should see a doctor at least once a year to get a checkup or physical and make sure you are running in tip top shape!

When you see your doctor, don't just listen, speak up! It is important to talk to your doctor about what is going on in your life. Only you know how you really feel and can provide the best insight or look into what is going on and what you think will help. It can be intimidating or scary to talk to your doctor, but remember, your doctor's job is to help YOU. So speak up! They might be the "professional" but you are the expert on you.

It can be difficult to remember everything you want to ask or tell your doctor during a visit, so it is a good idea to keep a list of things you want to discuss. You can add to your list as you get more ideas. Below is an example of the list I bring to my psychiatrist:

1) I talk to my doctor about how I am feeling that day and how I have felt since my last visit – I have Bipolar Disorder (a mood disorder like Depression) which affects my mood. If I have been having a lot of mood swings, that can be a warning sign that things are not going well and I might need my medications adjusted or changed. Even if you do not have a diagnosed mental health disorder it is still important to share your feelings with your doctor. Being honest with your doctor about how you've been feeling is important because if you are depressed or have been experiencing trouble they can help you.

2) I talk to my doctor about my sleeping patterns and eating habits since my last visit. For example, with Bipolar Disorder you can experience increased energy and a need for less sleep and sometimes appetite changes. It is important to share this type of information with your doctor so they know if you are in a stable place or not. It is important for everyone to talk about odd appetite and sleep patterns because this can reflect different health problems.

3) I talk to my doctor about any stressors that may be coming up – Stressful life events can cause mood disorders to get worse and these events can also cause physical health problems if you do not manage them well. Talking to your doctor about stressful life events is important because your doctor can help you with coping techniques so you are better prepared to handle them. This way you avoid having emotional or physical problems as a result of stress.

4) I share personal facts with my doctor – It is important to build a relationship with your doctor so they really know you and can help you. I tell my doctor about my triumphs and struggles so we have a personal relationship. For example, I share with my doctor when I get good grades and when I have rough days. It helps my doctor get to know me and this leads to better care.

Activity

Think of some questions you might want to ask your doctor! Having a parent or guardian help brainstorm possible questions or information to share can be really helpful too.

1)

2)

3)

Organization of Medical Information

The organization of medical information is necessary in order to maintain your health. It is important to keep all information, especially insurance cards, in one central place where you can retrieve it quickly. A folder or binder is a great place to store medical information. The folder can be divided up with tabs which can be purchased at an office supply store. The folder needs to be kept in a safe convenient place. Paper records should be kept in conjunction with online records. Any paperwork or documentation that you have must be kept for at least seven years.

The organization of medical information can be done at home or on the go. The items you should always carry with you in a wallet or purse include insurance cards, social security card, the names/numbers of doctors or clinics, and driver's license or identification card. These items are necessary in an emergency or when you visit any health care facility.

If you're organized, you will be able to find all information in an instant.

First Aid and Medical Emergencies

Gillian on First Aid and Medical Emergencies

Going through my years of education at Edinboro University of Pennsylvania with an uncontrolled seizure disorder of epilepsy helped me create a personal story of what I went through and managed.

Before starting college, I had a meeting with many faculty members of the school including the Office for Students with Disabilities, the Personal Care Assistants, and some Deans about what assistance I needed and what would need to be done in certain situations when I had a seizure. As a result of the meetings, it was decided that I would stay in the dorms for students with disabilities who needed personal care assistance in their daily lives.

As it turned out, when I needed to be given an emergency medication the EMS was required to be called even though it was no emergency. It was because it was a controlled medication I needed to be given, and it was inserted rectally. It was then also required for me to go to the hospital if I was given the special medication by the EMS. Doing that the EMS was wasting taxes on ambulance calls.

Going through the next year, things started to change some. The campus security would be called during an emergency and would try to transport me over to the campus medical center for the registered nurses there to give me the special medication. Being registered nurses, I was then not required to go to the hospital if I was given it. That went well for a while but then no longer did because an officer almost ran over a student as he was transporting me to the medical center. Once that went on, things went back to the way they were before.

To solve things I had my doctor write letters, an attorney become involved, and someone from the epilepsy foundation be involved. The president of the EMS had to be talked to so he would understand things, and how taxes were just being wasted as well. That was pointed out to him. The school policy would not change, so it was only the EMS who was permitted to give me the special medication.

Things eventually were worked out in a good way. The EMS learned that after they gave me the special medication they only needed to stay with me until I was completely out of the seizure and did not need to take me to the hospital. I then eventually learned to talk with the EMS president in a fun and friendly way.

First Aid and Medical Emergencies

It is good to know how to handle a medical emergency that may occur, being a person with a disability. There are varieties of things that can help you be prepared.

Who Needs To Know

There are people you should give explanations to on what to do when you may have a medical emergency. You may also need to explain the times when you need it and when you do not so they do not get confused. I needed to do that so people understood what seizures of mine were considered ordinary and what were considered an emergency. The people you should make sure know what to do are:

- parents/siblings
- friends
- roommates
- neighbors
- teachers/professors

Make a Contact List

You should also make yourself a contact list of who to contact in case of an emergency and always carry it with you. Some people who could be on your contact list include ones given an explanation to. They could be:

- parents/siblings
- friends
- roommates
- neighbors

Women's Sexual Health

Allsion on Sexual Health

Maintaining Confidentiality

Anything that you discuss with your doctor pertaining to your sexual health should remain completely confidential. Parents and family members cannot ask the doctor to divulge information that you don't want them to know for whatever reason. Most doctors are respectful of this, but some might feel that because you have a disability, it gives them the right to discuss confidential information with other people. If you fear that this might happen to you, it is important to tell your doctor that you are capable of making your own decisions, and that you want to be treated with the same respect as others.

Basics of Obtaining Contraception

Although abstinence (not having sex) is the safest form of birth control, when you choose to be sexually active, there are various places to obtain contraception. You could get it from your Primary Care Physician or gynecologist. You could also go to an agency like Planned Parenthood (http://www.plannedparenthood.org/health-topics/birth-control) if you don't have insurance or can't afford co-pays.

Finding an Accessible Gynecologist

As a woman with a disability, it may be difficult to find gynecologists whose offices and medical equipment are accessible. Fortunately, there are hospitals and clinics which serve the needs of women with disabilities. The examination tables and equipment are specially designed to meet the needs of women with disabilities, and the staff is trained to accommodate different types of disabilities. Many hospitals and physicians can provide referral service to help you find an accessible facility in your location. You can always call various doctors and ask if their office is accessible.

Maintaining Medical Equipment

Maintenance of Medical Equipment

The first thing a person should understand is the difference between durable medical equipment and assistive technology. Durable medical equipment is any device, such as a wheelchair or scooter, which is medically necessary to perform daily activities. It is a classification typically used by Medicare.

Assistive technology is any technology that improves the daily functioning of a person with a disability. Assistive technology, such as screen reading software or environmental controls, utilizes technology that needs maintenance as well.

The maintenance of your medical equipment or assistive technology is just as important as the maintenance of a car.

Here are a few tips to keep your equipment or technology in working order:

- Clean the devices on a regular basis. Dust or dirt could affect the overall performance.
- Make yearly appointments for general repair and preventative maintenance with supplier of devices.
- Keep equipment or technology out of the rain if possible.
- Budget money for future problems or upgrades.
- Use the devices as the manufacturer intends. For instance, a wheelchair is not an all-terrain vehicle or boat.
- Charge any rechargeable device on a regular basis.
- Check to see if batteries in devices are working properly.
- Fix minor problems before they get any worse.

Center for Assistive Technology

Pennsylvania's Initiative on Assistive Technology (PIAT) is a great source to find out about assistive technology (AT) and medical equipment. Their mission is to enhance the lives of people with disabilities through access of AT devices and services, which allow for choice, control and independence at home, work, school, and in their neighborhoods.

PIAT's website is filled with great resources: http://disabilities.temple.edu/programs/assistive/piat/. Here are a few examples:

- **Access to Assistive Technology (AT), or "How Do I Know What I Need?"**
  - **Device Demonstrations**—A hands-on opportunity to learn more about different AT devices so individuals can make an informed choice about what will work best for them. For more information, email ATdemo@temple.edu.
  - **Device Loans**—Pennsylvanians of any age and ability can borrow AT devices, at no cost, to try at work, school, and home or in their neighborhoods. This short-term loan program has a "try before you buy" philosophy, and helps people with disabilities and their families make the right choice of AT devices before they obtain a device. For more information, email ATlend@temple.edu.

- **Acquisition of Assistive Technology, or "How Do I Get What I Need?"**—Device Reutilization and Recycling: Previously owned devices are an affordable option instead of buying new, and several options are available to Pennsylvanians, including classified listing of used devices (REEP), an online auction site (www.ATMATCH.com) and refurbishing programs (Into New Hands and Liberty Wheels). For more information, email ATreuse@temple.edu.

In addition to these Access and Acquisition activities, PIAT also provides:

- **Training**—Outreach to service providers to increase their AT-related knowledge and skills to better support people with disabilities. For more information, email ATinfo@temple.edu.

- **Technical Assistance**—Outreach to public and private agencies to develop and improve policies related to AT as well as transition from school to work or from nursing home to community living. For more information, email piat@temple.edu.

- **Public Awareness Activities**—Information and referral which educates consumers, via phone, email or letter, about their choices of AT devices and services; AT exhibits and presentations at conferences, group meetings, staff in-services, and other events; and Case Management to help consumers navigate the maze of funding options available to obtain needed AT. For more information, call 1-800-204-9428 or email ATinfo@temple.edu.

Center for Assistive Technology

The Center for Assistive Technology is a place that assists individuals with disabilities in obtaining appropriate assistive technology. It is a great resource for medical equipment and assistive technology. It is located in the Oakland section of Pittsburgh at the Forbes Tower. It is known as the CAT by many people. The CAT provides comprehensive services from technology consultation to adaptive driving evaluation and training. There are experts at the CAT who are caring and helpful. They provide either commercially available or customized assistive technology to improve the lives of persons with disabilities. The technology suppliers who work with the CAT have extensive knowledge regarding both simple and complex assistive technology. Here is the contact information for the Center for Assistive Technology:

UPMC Health System
Forbes Tower, Suite 3010
200 Lothrop St.
Pittsburgh, PA 15213-2582
Voice: 412-647-1310
TDD: 412-647-1325
Fax: 412-647-1322
Website: http://www.cat.pitt.edu

Working with Personal Care Assistants

Josie's Views: Juggling having a Personal Care Attendant (PCA) and a personal life

I have had nurses for my entire life and have hired my own PCAs for the past six years. Although I love having PCAs and the freedom it has given me, it can be hard to maintain privacy or a private life. While having PCAs I have had to figure out how to manage friendships, dating, and personal problems.

One question I always struggle with is "how can I have privacy when I have somebody with me 24 hours a day?" I cannot give you the perfect solutions, but I will try to give you a few tips that have helped me stay sane and continue to have a private life.

Personal Space and Alone Time

I have had to learn that it is ok to ask for alone time. For a few years, I felt that I needed to entertain my PCAs and keep them busy. This was draining and made me realize how much I needed alone time. Now, I try to set time aside everyday and on the weekends to be alone. When you have full time attendants, it is easy to lose "alone time" and time to reflect. It is critical to make an effort to do this, even if it is only for 15 minutes a day. You may be able to use the following suggestions to help you manage having alone time

- Before going to sleep every night, spend some alone time reflecting, writing, reading, or listening to music. Do something that you enjoy doing and that can help you unwind.
- After school or work take a half hour nap. Sometimes it is helpful to not talk to anyone for a bit of time after a stressful day.
- Set time aside to take a relaxing bath or shower. Even a 10 minute shower can give you time to "get away" and think.

- Find a mode of art. Sometimes art can help you to explain your feelings and release your stress. This may be a great way to have alone time to reflect.

Friendships

Every person has different ways of interacting with their friends and PCAs. Sometimes it is hard to figure out where to have a care attendant go with you and how involved they should be in your friendships. It is OK to keep your PCAs and friendships separate. However, when I hire PCAs, I prefer to hire people that I know that I could form friendships with. In doing this, I am able to have an attendant and spend time with a friend. Don't forget though, that these friends are still working for you and that you are paying them to help you.

Dating

Needing a care attendant and being in a dating relationship can be one of the most difficult situations to balance. On one hand, you do not want your significant other to be providing all of your care so it is nice to have a care attendant around. On the other hand it can be very awkward to have your PCA with you during intimate times. Here are a few suggestions that have worked for me:

- Have your PCA get everything set up and taken care of before your significant other arrives. This will help you to be as independent as possible without having your attendant with you.
- Have your attendant stay in a room near you but not in the same room. This will allow you to call them if you need them but also give you some privacy.
- Plan a double date with your boyfriend/girlfriend, PCA, and their boyfriend/girlfriend. This will allow you to have an attendant but make it seem less awkward.

Important Definitions

Many helpers are health care professionals, and they usually have different skills depending on their training. This training will enable your helper to take on different responsibilities. These helpers each have different job titles to clarify their different job duties. There titles are often represented by acronyms. All those acronyms can be confusing and make you wonder "what does that actually mean?"

Here are a few common helpers and what their responsibilities entail:

RN: Registered Nurse

- The RN role is mainly a supervisory position and requires two to four years of nursing school in order to obtain an Associate's Degree. A RN provides direct care and also dispenses medication to individuals.

LPN: Licensed Professional Nurse

- An LPN usually provides direct care to individuals while in a medical setting and has attended a vocational school to attain their title.

CNA: Certified Nurse's Aides

- A CNA works under the supervision of nurses, rehabilitation therapists, etc. and the certification for this position varies by state. Most CNAs work at home care agencies and aid persons with daily living activities.

PCA: Personal Care Attendant

- A PCA provides direct care to individuals usually in the home care setting and requires training or a certification.

Directing One's Own Helpers

People with disabilities may have personal care attendants (also known as personal attendants, aides, PCAs, or PAs) for various reasons. Personal Care Attendants can assist individuals with all types of disabilities and can provide various services. Some PCAs may help with cooking, shopping, cleaning, staying on task, navigation, and various other tasks. Many agencies help pay for personal care attendants, however, the client (person with the disability) should always be in charge of the care they are receiving from their PCA. Sometimes it is difficult to know how to direct your own care and lead an independent life.

Self-advocacy and self-determination are important in learning how to direct your care. You must be able to communicate your needs and wants with your PCA while also respecting the needs and feelings of your attendant.

To have a successful relationship with your PCA:

- **Show respect**- even though your PCA is there to support YOU, they are not your slave. Just like any person with any job, your PCA's work with you is only one part of their life. S/he has a life too, and may not be able to work for you every time you need it. Make sure to have enough PCAs to cover all the shifts you might need and fill in when necessary.
- **Communication** is KEY- Even though your PCA may know you very well he or she is not psychic. We are all human, even your PCAs. There will be times that you will need to remind them of things that need to be done or explain to them what you want (or re-explain to them how to do something). You need to be able to tell them what you need and want and how that should be done. While you should not be afraid to be specific, you should also keep the previous point of RESPECT in mind.
- **Building a Relationship** with your PCA- Although the main purpose of having a PCA is to provide for your care, friendships can also be formed within this relationship. For example, a PCA may help you with cleaning your apartment, however, they may also go to a movie with you and your other friends.

Just like no person is the same, no PCA-client relationship is the same. Some relationships are very open while others are more strict and business like. Every PCA is different and they will not do things in exactly the same way. Sometimes it can be difficult to get used to the style of each PCA but as long as they get the job done correctly, that is all that should matter.

You and Your Helper: Safety Comes First

Your comfort and safety should be the top priority when dealing with helpers! Because the role of a care attendant can be very intimate (helping the client change clothes, manage money, etc), you need to understand the importance of selecting staff who can work well with you. Not everybody is meant to be a PCA or nurse, and unfortunately most of us who need care attendants have hired at least one of these people.

There are cases in which care attendants have taken advantage of the client, including sexual abuse, theft (including identity), and many other criminal acts. Having a care attendant means that you need to know how to avoid hiring people who could put you in dangerous situations, and what to do if you do hire one.

Clearly communicate to your helper if he/she is not properly assisting you or if you feel unsafe at any moment. Give suggestions on what your helper can do to correctly give you the best care in order to remain safe, secure, and comfortable.

If problems do arise and your safety is jeopardized, TELL SOMEONE! Report any problems with your helper to other medical care professionals, nursing agencies, family members, etc. It is completely acceptable to report any wrongdoings because you need to be helped safely and appropriately.

How to avoid hiring a bad care attendant

- Create an application that asks:
    - Past job experience and work experience.
    - Why they want the job.
    - Address and phone number.

- Personal and professional references.

- Do interviews:
  - Take notes so you don't forget who each person is.
  - See if another person (friend, family member, etc) can listen in to the interviews with you.

- Call references and current/former employers:
  - Ask about their character, how they know the person
  - Ask employers about their attendance record, and would they hire them again.

What to do if you do hire a bad personal care attendant:

- If they are doing something illegal call the police- Dial 911
- Contact a disability service provider- if you get your attendants through an agency, call them immediately
- If you are hurt or have been raped go to the Emergency Room- Dial 911
- Call or email an advocate to help you talk to authorities- Pennsylvania Protection and Advocacy and Centers for Independent Living can help

Activity

Everyone's Helper is Different

Worksheet: We each need different types of help and we each have our own definition of what a helper is! For some a helper can be their parent, for others it is a hired professional – different help comes from different people.

1. How would you define a helper?

2. What types of helpers do you have? What do they generally do for you?

Now that you can identify some of the different roles of helpers, it is important for you to identify the assistance you need. Your helper can provide better care if *you* know what assistance is necessary.

Creating a Checklist for Your Helper

Worksheet: There can be many duties your helper may need to provide, so it is extremely important to be organized and prepared.

1. What can your helper assist you with on a daily/weekly/etc. basis?

2. Create a checklist that you can have for reference and your helper can view as well. Be sure to include all of the activities you listed above so that you do not forget all of the necessary help you need.

3. Communicating to your helper how each item on the checklist should be done is very important. What is your personal routine or way of doing each item? Write specific notes about each item in the space below.

Activity

Safety is ALWAYS a Priority

Worksheet: You need to be aware of how to handle any problems that may arise with your helper.

1. What would you do if you felt unsafe with your helper?

2. Who would you contact if a problem existed with your helper? What would you say to whomever you contacted?

Think You Have the Hang of It?

Directing one's helpers takes some effort, but mapping out what you need help with and being prepared for their assistance can make a huge difference in the entire experience. Speak up about how your helper can provide better care and keep the lines of communication open.

Your helper wants to be there for you in any way he/she can and make you feel comfortable, so remember that when directing your helpers. Always keep your safety as a priority, and therefore, you can feel safe while obtaining the assistance you need!

Communication is Key

In summary, make sure your helper knows your needs! Communication is helpful to both you and your helper to create a comfortable, positive environment. Keep in mind that every person has different needs and you should be direct in terms of expressing the best process for each activity.