Indiana Disability Conference

“Helping Caregivers Transition from Stress & Anxiety to Confidence & Peace of Mind”
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• Welcome

• Thank you

• Background
“Helping Caregivers Transition from Stress & Anxiety to Confidence & Peace of Mind”

This session is about six simple steps that will help you to transition from Stress & Anxiety to Confidence & Peace of Mind.

Since the layers of personal health information are practically endless, things may seem overwhelming.

**But there is something calming about taking steps of preparation!**
Each step prepares you for the unexpected in the medical realm:

- The next dr. visit
- The next therapy
- The next hospital stay
- etc....

Each step frees up a little more of yourself.
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Before we start, give yourself permission to take a step back, take a deep breath, calm yourself and put your mind in neutral.

Relax.
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People will not necessarily have the same diagnosis but what we do have in common is the feeling of drowning in the amount of information that we need to manage.

Question:
“How do you eat an elephant?”

Answer: "one bite at a time..."
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Step 1 – A New Change

Our elephant takes on the form of endless detailed information we needed to have as we were caring for our loved one.

Trying to remember this information always made us feel like we were drowning.

Question: “What are some questions that a patient is asked at every dr. visit?”

Examples:

What is the patient’s date of birth?

Does the patient have any allergies?

What are the names, dosages, and frequencies of medications the patient is taking?
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Step 1 – A New Change

To answer these questions, we created a simple “Current Status” page to capture this initial critical information.

Once we had this information with us, we were still a little overwhelmed, but we no longer felt like we were drowning.

....On to Step 2 – A New Surrounding
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Step 2 – A New Surrounding

With chronic or serious medical issues, now you find yourself in a new place.

We still had an ocean to deal with, but we needed to get used to our new surroundings.

What is your new surrounding?

- Is it a hospital room with or without a view?

- Is it a bedroom converted into a makeshift hospital room with various medical equipment and medicines?

- Maybe it is a bedroom that needs to change into a “safe” zone.
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Step 2 – A New Surrounding

People stop living life because they do not feel comfortable leaving their home.

Wouldn't it feel great to be able to leave home and know that your loved one is safely cared for?

Here are questions that may be holding you back:

- What happens in the case of a fire?
- Where is the first aid kit in the home?
- What are the nearest crossroads when giving directions to 911 personnel?
- What to do if the power goes out?
- Who are my primary emergency emergency contacts?
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Step 2 – A New Surrounding

Taking this step is like receiving a life preserver that you can use to stay afloat.

....On to Step 3 – A New Partnership
Step 3 – A New Partnership

We have gone from the feeling of drowning, to having a life preserver. Now it is time to get help.

Caregivers are helped by a host of different individuals and agencies.

It is important to write down and detail out who these various partners are. As you are building your circle of care team, you need to know who you can call and count on for assistance.
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Step 3 – A New Partnership

- Schools
- Nurses
- DME Providers
- Legal Consultants
- Therapists
- Doctors
- Hospitals
- Government Agencies
- Government Agencies
Step 3 – A New Partnership

Once you’ve built your “circle of care” team, you will be able be a better advocate for your loved one.

Over time, you and your team will begin to collaborate in the care of your loved-one.

From Emotions to Advocacy - Pam and Peter Wright

....On to Step 4 – A New Routine
Step 4 – A New Routine

Now that we are afloat, we start to feel more normal. Floating can be soothing when the waters are calm.

But dealing with a chronic illness or disability tends to stir up the waters and keep you from your normal routine.

Since a healthy routine helps to bring simplicity, structure, and order out of chaos, we need to do something to bring it back.

Documenting your loved-ones’ daily routine does that and helps:

- You
- Your loved-one
- Others who help care for your loved-one
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Step 4 – A New Routine

Some things to document:
- Wake-up time
- Therapy schedule
- Medication schedule
- Favorite TV show and schedule
- Daily activities
- Music time
- Nap time
- School time and bus schedule

This new routine will help you to find balance with living life and living life with an illness.

....On to Step 5 – A New Loved-One
Step 5 – A New Loved-One

When the waters are rough, being prepared allows you to ride the waves.

With a chronic condition you must now know what things to do and what things to avoid. This is especially important during an emergency crisis.

Your ability to communicate critical do’s and don’ts to emergency personnel may mean the difference between life and death.

For instance:

- Are there certain medications that he/she should not take?
- Are there foods he/she cannot eat?
- Does he/she have advanced directives?
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Step 5 – A New Loved-One

Having emergency information written down will help you to stay calm when it comes to making life altering decisions. You will be able to stay “in the moment” with your loved-one.

Dealing with chronic illness and disability on a daily basis brings about a certain level of preparedness. Over time you realize the more you have things written down, decisions made, and awkward conversations started, the easier the process gets and the less stress you feel.

....On to Step 6 – A New You
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Step 6 – A New You

Whether you are on a serene lake or in rough deep waters, you are able to find confidence and peace; despite the ups and downs life brings.

This last step rounds out the information necessary for your loved-one’s circle of care. These details include contact information of your loved one’s family, friends, work, school, church, and extended caregivers; like babysitters or neighbors.

Although this is the last step of the series, it is only a further step towards the development of the “New You” and the “New Normal” of your life. By now, you are not just surviving in this new life, you are thriving!
Step 6 – A New You

You now have a better handle on the illness, what it means to you and your family, and the changes that come with it.

No longer are the challenges of illness and disability weighing you down because of doubt and uncertainty. You have taken steps to become more involved in their care, more proactive in their health, and more confident of the decisions that need to be made on their behalf.