

These are notes compiled from the "Life Hacks" session from the 2017 A-T Caregiver Weekend. During this session, caregivers shared and discussed ideas for life hacks. This document captures the conversation from the weekend and is not meant to stand on its own as recommendations.

LIFE HACKS

Learn from each other about how assistive technology, adaptive equipment, and home modifications can make life a little easier.

HOUSE

- Make the house more open
- Transfer pole is better than grab bar
 - o Stand upright
 - o Cheap
 - o Removable
 - o Can be used in the bedroom or bathroom
- Install handrails in house – especially in hallways and dining room
- Door knob – lever handles from knobs
- Extra-thick foam floor mats
- Larger size bed – platform bed lower to the floor is good
- Add rings to door frames – good for upper body exercise
- Stair lift that is not a chair – child stays in the wheelchair
- Anderson – accessible door, 36" wide
- Take box spring out of bed to lower it, and add slats instead
- Ceiling lift
- Portable lift
- Pivot bars
- Pocket doors
- Remote-controlled blinds
- Tip: oak is as strong as stone – good for baseboards and handrails
- Wireless doorbell to get attention at night
- Dyson sticky material
- Base cabinet with contoured back
- Homemade walking stick to turn lights on
- Padding everywhere – yoga mats
- Monoprice – triple hinge TV stand for feeding pump in bedroom – you can swing it in and out easily
- Folding ramps for curbs, garage, and car
- Stair lift
- Wide doorways: French doors, pocket doors
- Move bed to floor to keep child from getting injured
- Bed side rail

BATHROOMS

- Washlet toilet seat/bidet

- Specific brand recommendation: Toto washlet
- Heated seat option
- Give A-T person more independence in the toilet
- About \$500
- Rifton toilet seat on wheels
- Potty seat or regular toilet seat with magnets to slow close – can be bought at Home Depot
- Bath lift
- Long grab bar by the toilet
- Shower bench
- Walk-in tub
- Soap on a rope
- Shower that is almost like a carwash
- Automatic (hand wave) soap dispenser
- Sits in garden chair in the shower
- Uses electric toothbrush

TECHNOLOGY

- Big keyboard
- Magnitto cable – easy to charge ipad/cell phone - \$18 on Amazon
- BJ live mouse
- iPad for communication
- Stickers for keyboard to make letters bigger

ACTIVITIES

- Special Tomato Jogger or Convaaid cruiser before wheelchair
- Gait belt for PT
- Sports
 - Horseback riding
 - Swimming (OT)
 - “Children at home” provides special contribution of \$2,000 toward adaptive activity
- Convey wheelchair/stroller
- Slant board
- Pre-cutting for crafting
- Magnetic chess board
- Scooter board – allows 360-degree rotation, both inside and at school
- Grid hand wheelchair
- Beach wheelchair that is portable
- Warm water massage therapy
- Sweat bands for drool – can color coordinate
- Card holders – can use a block of wood to lean cards on
- Always rest the day after a big activity when traveling

EATING

- Adjustable special tomato high chair – can use from pre-school up to ~4th grade
 - o Good for back support and foot support
 - o Use at school and home
- Adjustable tables
- Adaptive chair that goes up and down
- Rubber/grip pads under plates and other tableware
- Rifton activity chair for dinner
- Hydroflask from REI – with straw from Amazon
- Silicon straw lids from Amazon
- Liftware fork/spoon
- Slo-flow straws
- Watercups with top and handle
- Suction cup that doesn't tip
- Collar around a plate – you can adjust it to any plate
- Weighted spoons

These are notes compiled from the "Live Your Best Life" session from the 2017 A-T Caregiver Weekend. During this session, caregivers shared and discussed ideas for living life to the fullest, in a speed-networking format. The specific topics of discussion included: "Best Suggestion/Ideas to Share," "Favorite Thing to Enjoy With Child," "Greatest Strength," "Biggest Challenge," and "Your Proudest moment of your A-T Child or Adult." This document captures the conversation from the weekend and is not meant to stand on its own as recommendations.

LIVE YOUR BEST LIFE

From adaptive sports, to family travel, to other recreational activities, brainstorm ideas for living life to the fullest.

BEST SUGGESTION/IDEAS TO SHARE

- Social life and friends
 - o Write a letter to the class that includes:
 - I'm paying attention
 - Don't be afraid of me
 - These are things that matter to me
 - Need respite hours
 - o "Hire" a bud – someone from college studying special ed
 - o Competitive A-T kid? → be a manager of the wrestling team, band, etc.
 - o Social does get harder the older they get
 - o Interaction with other A-T kids is great
- Grading
 - o Only test over the critical items
 - o State tests – can you opt out? Check with each state
 - o How are they earning their grade?
 - o Oral testing is a good option
 - o Vocation rehabilitation
 - o IEP – less is more, aide should not do the homework
 - o Shorten assignments
- As a parent, would you go in the classroom to explain A-T?
- Give breaks – need time to recharge
- Being social is important – stay connected with friends
- Adaptive sports (gymnastics is great)
- Live their life
- Travel
- Keep older kids active
- Letting them try things they want to try
- Get them involved in whatever they want to do, no matter what that means
- Have them do research to plan, or help plan vacations
- Volunteer ideas: hospital, restaurant, food banks
- Audit community college, day programs
- Mom and pop stores – do not recommend the large big box stores or corporations
- Power chair – can be used for delivering mail
- Sports – special Olympics
- Work ideas: shredding, website, consignment store

- Volunteering work ideas: coordinating events at arena/day camp, socializing animals, working at daycare
- Gym
- Personal Care Assistants (PCAs) – go to the movies, personal care
- Home jobs: empty dishwasher, put clothes away, set table, cut veggies, dust, Swiffer
- Follow PT/stretches on own
- Horse therapy
- Swim therapy

FAVORITE THING TO ENJOY WITH CHILD

- Dancing
- Spending time/hanging out
- Reading
- Shopping
- Going out to eat
- Helping in the kitchen/cooking
- Fishing
- Watching shows together
- Hide + seek
- Going to dinner
- Comic-con
- NOT homework 😊
- Travel
- Being outdoors – hiking
- Waterski
- Dirt biking
- Adaptive sports: track, rock climbing, race chairs
- Indoor parachute/wind tunnel

GREATEST STRENGTH

- Good sense of humor
- Fierce determination
- Expressing his/her emotions
- Enjoys working hard and competition
- Perseverance
- Strong-willed
- Faith in God
- Cares about others
- Stubbornness
- Curiosity
- Memory (doesn't forget anything)
- Tough and doesn't complain
- Willing to try anything
- Very loving
- Happiest kid – always smiles

- Good negotiators
- Make people laugh and have fun

BIGGEST CHALLENGE

- Letting go
- Giving lots of experiences
- Adapting their environment as children get older
- Keeping active as they age
- Getting to socialize
- Work life
- House situation
- Frustration due to lack of independence
- Loneliness
- Loves to do things, but gets tired
- Transportation for independence in the community is a challenge
- Difficulty getting a job
- Stress between couples and/or caregivers
- Bathroom
- Programs often for those who are mentally challenged
- Little tasks that require using hands
- Day habilitation centers (day habs)- hard to find correct fit

These are notes compiled from the “Caring for Yourself (While Caring for Everyone Else)” session from the 2017 A-T Caregiver Weekend. During this session, caregivers shared tips and suggestions on how they care for themselves. This document captures the conversation from the weekend and is not meant to stand on its own as recommendations.

CARING FOR YOURSELF (WHILE CARING FOR EVERYONE ELSE)

What are your best tips to make sure that you stay energized and healthy?

- Dinner and movie
- One parent not working
- Biking, running
- Babysitter 2 evenings/week
- Workout: boxing, exercise, hip hop dancing, cardio, barre, lifting weights
- Talk with others, friends
- Mom playdate with just moms
- Work
- Having adult time with spouse after kids’ bedtime
- Family dinners, family time, family vacations
- One-on-one trips with A-T kids
- Go to A-T conferences and workshops
- Fundraising – GOOD for the mind
- Going to the beach
- Being outside
- Stay positive and not always discussing the things going wrong
- Find a way to laugh
- Couples counseling
- Mother’s night (friendships) out
- Date night – dinner out, club (music), couples painting – remember each other
- Physical stuff – gardening, yard work, work around the house, landscaping
- Mani/pedi, massage every now and again
- Change scenery – get away and relax
- Sleep – are you getting enough?
- Take a few hours by oneself to read
- Talking with family
- Open up to others; developing support group
- Cry together
- Don’t do too much – cut back, let go, don’t over-schedule afterschool, club, sports
- Medication for depression
- Taking date nights
- Travel without kids
- Getting up early for “me time”
- Finding a job that fits your schedule – maybe it’s stay-at-home
 - o Taking care of your own kids and getting paid as a certified nursing assistant (CNA)
 - o Stay-at-home waivers from Medicaid
- Assistive Device Program (ADP) in Canada – disability tax credit

- Disability nonprofits may assist with equipment – “Easter Seals,” county programs
- Morning coffee
- Hula hoop
- Connect with a friend that has similar situation to vent
- Binge watch shows
- Listen to a lot of music
- Lunch with friends
- Jacuzzi
- Biking inside or out – motorized 3-person bike
- Guided imagery meditation
- Essential oils
- Hopekids.org
- Screaming at the top of your lungs in a fast-moving car
- Punch your pillow
- Get enough helpers
- Games for competition – Scrabble
- Comedy show
- Sit by the water
- Write in journal
- Laughing
- Craft-work
- Keep your mind busy