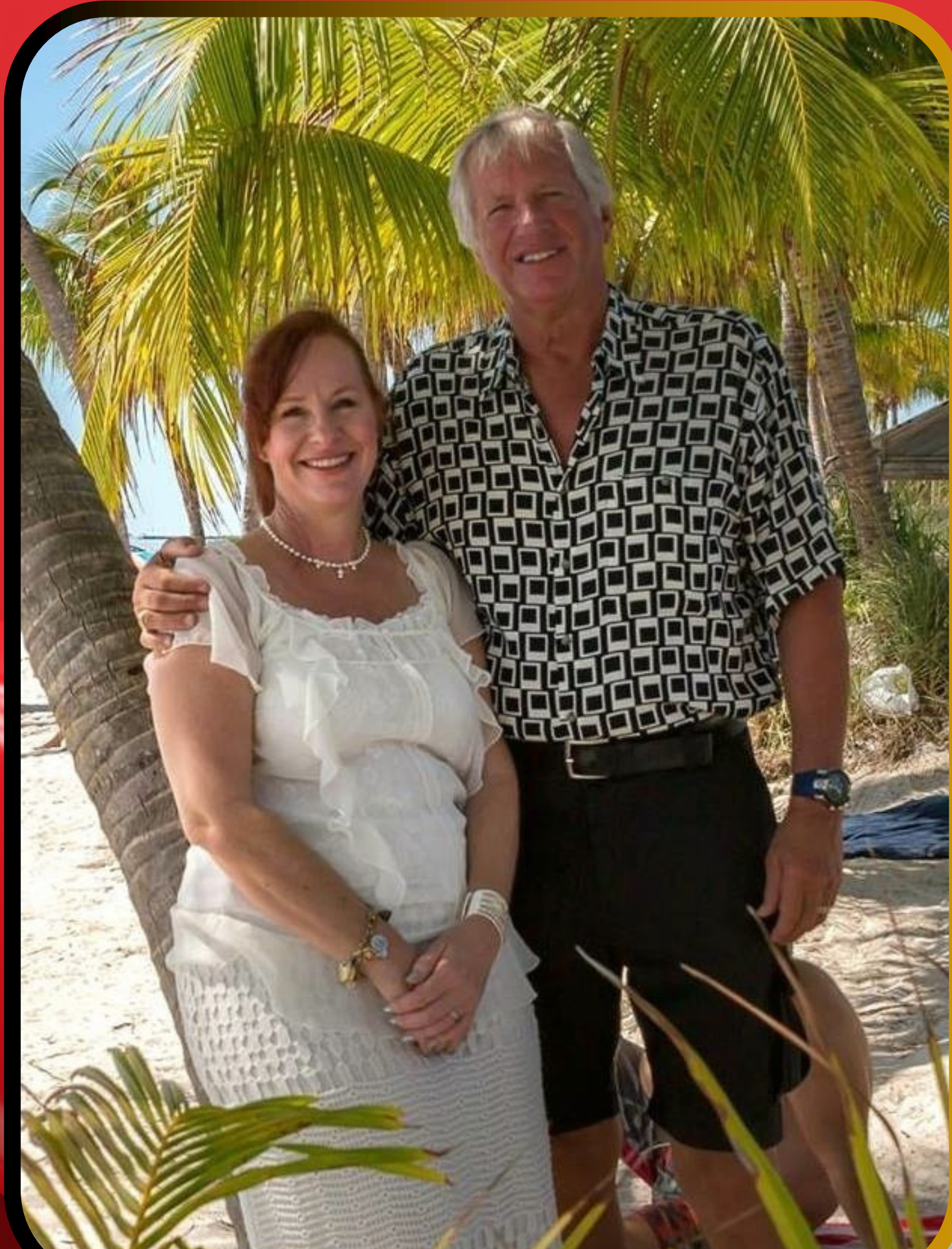


CARING FOR ALS: WHAT I WISH I KNEW

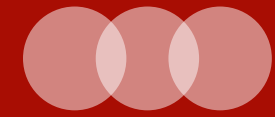
Melissa Alice Jones, PA





FIRST STEPS

- **START A FILE/BINDER CONTAINING ALL DIAGNOSIS FROM ALL DISCIPLINES**
- **GET FINAL PAPERWORK DONE**
 - *** Will
 - *** Durable POA
 - *** Living Will
 - *** ID & Medical Cards
 - *** Healthcare Insurance - Start now for caregivers etc.
- **HANDICAPPED VAN - Rental/Purchase 954-357-8400 or www.broward.org/BCT**
- **GET ON SUPPORT GROUPS**
- **DECISION ON END OF LIFE**



2. WHEELCHAIRS

- ALS ASSOCIATION (CLOSET) TO BORROW EQUIPMENT IE ELECTRIC PATIENT LIFT, MOTORIZED WHEELCHAIR



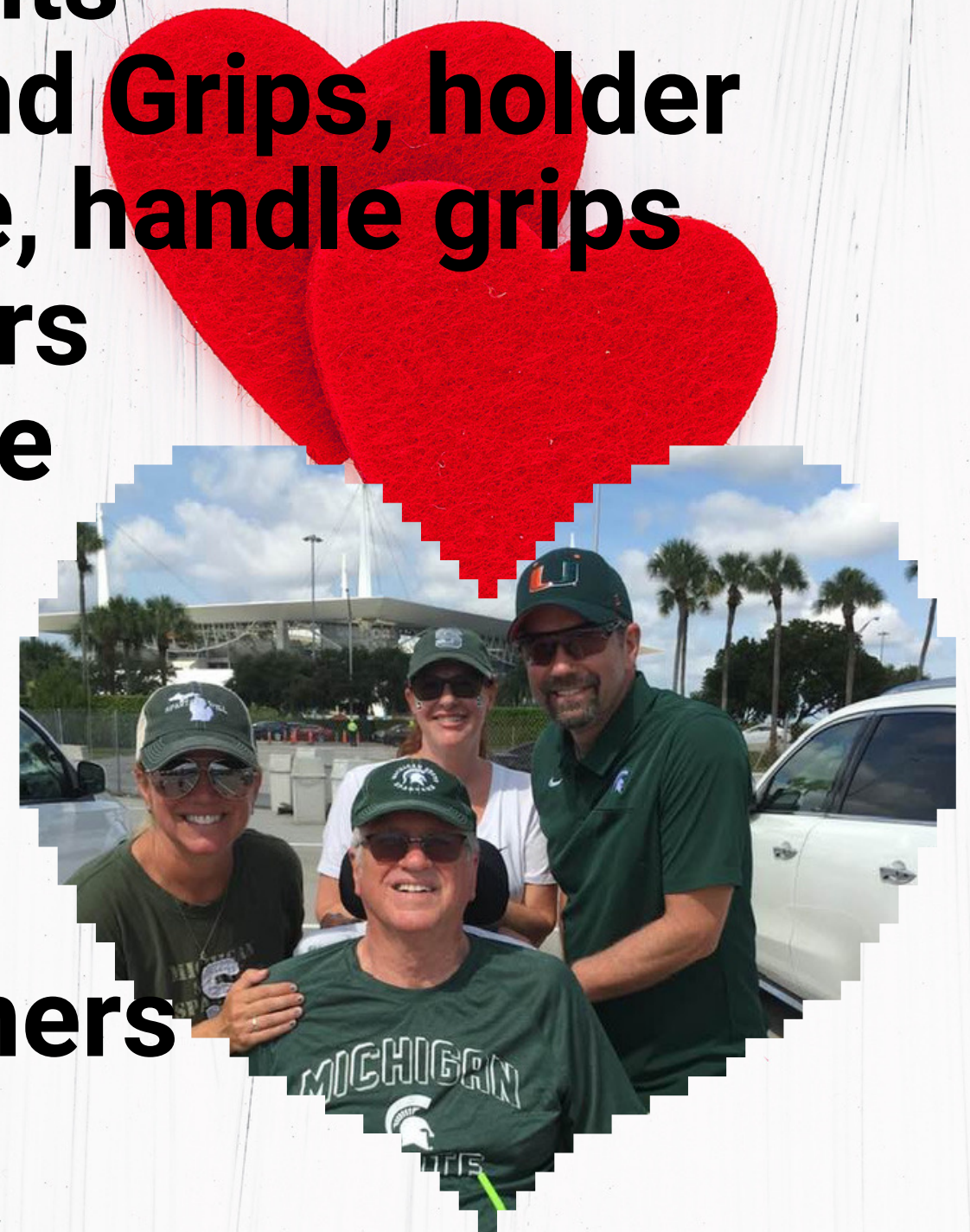
3. NECESSARY TOOLS & EQUIPMENT

- Transfer board/sheets
- Alternating pressure pad for bed
- Shower/Bathtub system ext.
- Gait Belts
- Bed assist rails - bed assist rope
- Bed wedge pillow
- Hoyer Lift – slings
- Risers for chairs
- High Toilet Seat/ Portable Potty
- Reacher or Grabber
- Adaptive Clothing - Hospital Gown
- Car Wash Mitts to put on metal foot pegs
- Trapeze for over bed to assist getting up



3. NECESSARY TOOLS & EQUIPMENT

- Lots of Lotion
- Calprotect Ointment
- Nasal Pads for Skin Breakdown or nose from BiPAP
- Inflatable Cushion, donut or tailbone pillow
- Recliner - measure patient
- Bathtub - shower sliding transfer bench
- Shower Chairs
- Noodles for everything - avoid damaging skin
- Caregiver wireless pager & Call Button
- Adult Diapers, Chucks for Bed Chair Accidents
- Assistive Hand Grips, holder for silverware, handle grips
- Leg massagers
- Hospital Table
- Urinals
- Pill Crushers
- Hydration
- Walkers
- Commode Liners
- Laxatives



“

4. TRAINING/ EDUCATION

- **END OF LIFE DOULA OR COACH**
- **BOOKS AND ARTICLES SPECIFIC ON ALS**
- **PHYSICAL & OCCUPATIONAL THERAPIST**



5. HELP

PEOPLE ASK "HOW CAN I HELP?"

- CAREGIVERS NEED RESPITE HELP - ACCEPT IT
- GIFT CARDS - LIFESAVER!
- GET CARETAKERS EARLY! TAKES A LONG TIME HERE IN SOUTH FLORIDA
- WHEN SHOULD I BRING IN HOSPICE?
- TOILETING



You're not **ALONE**

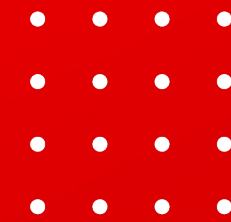
- YOU MUST BE ADVOCATE FOR PATIENT
- INTERVIEW HOSPICE ORGANIZATIONS BEFORE YOU DECIDE

GOOD THINGS



- CAN EAT ICE CREAM EVERY MEAL WITH EVERY TOPPINGS!
- NON-PHYSICAL INTIMACY WAS PHENOMENAL






More Questions?

**Get in Touch with
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Thank You!!!