Welcome!

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How to Stay Connected
In a Changing Environment

Guest Speaker:
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The ALS Association
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Staying Connected during the Coronavirus Pandemic – Facebook
Smart Speakers, Apps and More!

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Caregivers are not allowed to ride along in an ambulance.

Most hospitals will NOT allow a visitor/caregiver in the Emergency Room.

No Visitors in hospitals during an in-patient stay.

No visitors allowed in nursing homes.

Due to COVID-19 (Coronavirus), NO VISITORS.
Go Bag

Content suggestions

- Copy of your Medical Insurance Cards
- Medical Card with ALS specific information
- Written list of phone numbers: doctors, pharmacy, and family contacts
- Written list of medications
- 7 days worth of medication
- Written directions on how to communicate with the person with ALS
- Letterboard
- Advance Directive
- Style/Serial number of medical devices
- Reading Glasses (dollar store will do)
- Wipes
- Phone Charger / Ear Buds
- Socks
- Pen and paper
Medical Information Packet

- The ALS Association website
  - www.alsa.org


- Allows user to fill out information regarding communication, swallowing, nutrition, mobility, respiratory issues, and others
  - Walks the user through all aspects
Communication Considerations

- Make sure your Medical Information Card explains the best method communication for you
- Store writing materials/letter board/key phrases in your emergency kit
- Determine how you will communicate with emergency personnel if you do not have your communication device
- Obtain an alternate power source for electronic means of communication
Communication Boards

- I can email you a link for you to print out
  - alisa@alsphiladelphia.org
- Website offering free downloadable communication boards
  - Patient Provider Communication
    - Bilingual available
Emergency Information List

• Personal Contacts
  – Local and out-of-town

• Who to call in case of Emergency
  – Make sure this is written on paper (and laminated) because you may not have access to your electronic device for stored numbers
  – Have physician and pharmacy numbers
  – Home Care Agencies
EMS/Emergency Room Considerations

I can not verbally speak but I understand everything you are saying.
I say YES by moving my eyes to MY RIGHT
I say NO by moving my eyes to MY LEFT
I say MAYBE by looking up

SHORTNESS OF BREATH:
If I display shortness of breath or low SpO2, do not give me oxygen unless I have another respiratory condition that requires it. I may need noninvasive positive pressure ventilation to expel CO2.

OXYGEN MAY NOT HELP AND MAY MASK RESPIRATORY FAILURE:
My lungs are healthy, but my muscles including diaphragm are weak. IF I am using a BPAP at home, the settings should be the same as those. IF NOT, a BPAP with a pressure of 12/6, backup rate of 10 with titration as needed may help.

LAYING ME ON MY BACK:
May be difficult for me because of the possibility of CO2 retention due to diaphragmatic weakness and aspiration due to poor ability to protect my airway. I may be able if using a BPAP or non-invasive mechanical ventilation.

AVOID:
Paralytic or general anesthetics, narcotics or muscle relaxants unless absolutely necessary. If used, the ability to rapidly assist ventilation non-invasively or invasively should be available.

If I have a gastrostomy tube, please use that for administration of “oral” medications.
Staying Connected – Hospital Stays

• **Built-in Apps**
  • If you already own a smartphone or tablet, you likely have a video chat app built into your device

• **Apple Devices – FaceTime**
  • Built into Apple iOS (iPhone, iPad, & iPod) devices and Mac computers
  • Calls are restricted to other FaceTime users

• **Android Devices – Google Duo**
  • Built into Android devices
  • [Free app for iOS users](https://ndassistive.org/blog/connectioninthewtimeofsocialdistancingpart2/)
  • Can also be accessed on a Mac or PC via [web browser](https://ndassistive.org/blog/connectioninthewtimeofsocialdistancingpart2/)
  • Google Duo calls can be placed using certain smart displays such as the Google Nest Hub Max
  • Nice option for cross-platform video chatting.
    - Samsung Galaxy phone to an iPhone --Google Duo to video allows chat with each other

• Source: [https://ndassistive.org/blog/connectioninthewtimeofsocialdistancingpart2/](https://ndassistive.org/blog/connectioninthewtimeofsocialdistancingpart2/)
Third-Party Messaging Apps

Third-party apps are those not built natively into a device’s operating system. These apps can be downloaded from either the Apple App Store for iOS devices or the Google Play Store for Android devices.

- **Facebook Messenger Video Calls**
  - Requires a free Facebook account
  - Free app for iOS and Android
  - Can be also accessed from Facebook on a Mac or PC
  - Easy-to-use on the Facebook Portal smart display

- **WhatsApp**
  - Requires a free WhatsApp account
  - Free app for iOS and Android
  - Free desktop app for Mac and PC
  - WhatsApp calls can be also be placed using a Facebook Portal smart display

- **Snapchat**
  - Requires a free Snapchat account
  - Free app for iOS and Android

Source: https://ndassistive.org/blog/connectioninthesocialdistancingpart2/
Phone/Tablet Holder is critical!

- Place one of these

In this
For those in Nursing Homes/In-Patient Hospice or those with little technology experience

Smart Speakers
- Video Screens allow users to see each other
- Amazon Echo and Google Home
Amazon Echo Spec

- Three different sizes and price points
  - The 10-inch Echo Show occupies the top of the line, with the largest screen, loudest speakers, and highest price, while the alarm clock-like Echo Show 5 is less expensive and fits much easier on a nightstand

$69.00  $99.00  $229.00
Smart Speakers can be set up in advance!

User’s Wi-Fi Network and Password is Known

- You can set up the Show before you ship it or deliver it as long as you know the Wi-Fi network name and password. Amazon has some good directions.

If you do not know the Wi-Fi information

- If there is someone at the person’s home/facility that can follow-step by step instructions to set it up, you can walk them through on the phone or provide them with an instruction sheet
- Another way would be to go to their home, to the outside only, of course, and somehow plug it into an external power source within Wi-Fi range, like the garage or exterior of building, and finish the setup

No Wi-Fi

- Use old smartphone and using it to create an internet hotspot (if they’re not in a cell service dead zone).
  - Add a line to your cell plan, plug the phone in somewhere unobtrusive in the home for continuous power
    - Activate the “personal hotspot” option in settings and connect the Echo Show
      - Does require the user charge the phone
Grandpad

Simple and secure tablet computer that digitally connects a senior or other user to their family and friends

- The user can easily view family photos and videos, play games, see weather for each family member, listen to music, check emails, make phone calls, place a video chat, and much more
- Does not require Wifi
- Monthly bill (no yearly contract)
- $40/month
- Currently out of stock so check website for details
  - www.grandpad.net
  -
Jitterbug Smart Phone

• Simple Smartphone
• Large touchscreen makes it even easier to read.
  – 13.0 Megapixel built-in camera with flash has easy-to-use photo sharing
• Simple menu organized in a single list with large letters and icons makes it easy to navigate.
• Easy-to-use smartphone with exclusive features that are only available on the GreatCall network
• No contracts or cancellation fees
• Affordable, flexible plans with data as low as $17.48 a month
• Currently available on Amazon and other sites
iPads

- iPad
  - Mini, Regular and Pro

- Can reduce icons as to lessen confusion

- Easy to understand
- Rated #1 for seniors by Tech Radar, Caring.com, and multiple other sites
Amazon Fire

- **Amazon Fire HD 10 Tablet**
  - Bargain tablet has a big, 10.1-inch display, and focuses on Amazon’s array of apps and services, including the Alexa assistant
    - This means users can control the tablet with voice as well as touch commands
    - Downside
      - Does not support Google apps like Gmail, Chrome, and YouTube. This limitation may be a dealbreaker for some users, but for Prime subscribers who mainly want a tablet for streaming media, web browsing and video chatting, this is an inexpensive yet functional option
  - $149.00 (currently in stock)
Facebook Portal

- **Facebook Portal** is a brand of smart displays developed in 2018 by **Facebook, Inc**.
  - The product line consists of four models (*Portal* ($129.00), *Portal Plus* ($229.00), *Portal Mini* ($79.00), and *Portal TV* $149.00) that provide video chat via **Facebook** Messenger and WhatsApp, augmented by a camera that can automatically zoom and track people's movements.
  - Lets you video chat with your **Facebook** friends (yes, you MUST have a FB account).
  - The unit sits on a desk or table or near your TV, and the camera follows as you walk around, so you can talk to someone completely hands-free while doing other things.
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