

ALS[®] **ASSOCIATION**

**Staying Connected during the Coronavirus Pandemic, the Holidays,
and Beyond –Smart Speakers, Apps and More!**

Alisa Brownlee, ATP, CLIPP, CAPS, WSP

Assistive Technology Specialist

The ALS Association National Office and Greater Philadelphia Chapter

abrownlee@alsa-national.org

About me

- Assistive Technology Professional
 - Specialty areas are communication, computer access, environmental controls, home modifications
 - Credentialed Assistive Technology Professional (ATP) through RESNA (Rehabilitation Engineering and Assistive Technology Society of North America)
 - Certified Living in Place Professional (CLIPP) through the Living in Place Institute
 - Certified Aging in Place (CAPS) through the National Association of Home Builders
 - Credentialed Wheelchair Service Provider (WSP) through the International Society of Wheelchair Professionals
 - Current RESNA Board Member
 - Current RESNA Faculty
- 24 years with the ALS Association
 - Greater Philadelphia Chapter
 - National Office

Welcome

- I have no actual or potential conflict of interest in relation to this program/presentation
- I have no financial interest regarding any product I am including in this presentation
- I will share my slides – email me
 - abrownlee@alsa-national.org

Emergency Preparedness and Coronavirus Pandemic

- ❖ 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
- 10 FOOT Phone Charger / Ear Buds
- Socks
- Pen and paper

Phone/Tablet Holder is critical!

- Place one of these



In this



Medical Information Packet

- The ALS Association website
 - www.alsa.org
- <http://www.alsa.org/als-care/resources/publications-videos/medical-information-packet>
- 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 of 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

A	B	C	D		
E	F	G	H		
I	J	K	L	M	N
O	P	Q	R	S	T
U	V	W	X	Y	Z
Space		Oops		end	



Communication Bards

- I can email you a link for you to print out
 - alisa@alsphiladelphia.org
- Website offering free downloadable communication boards
 - Patient Provider Communication
 - <https://www.patientprovidercommunication.org/supporting-communication-covid-19.htm>
 - Bilingual available

FREE communication tools for patients with COVID-19

Download, print, & use!
+ more FREE resources

SUCTION	VENTILATOR	YES		NO							
SUCTION	VENTILATOR	DON'T KNOW		LATER							
PAIN	BREATHING TUBE	MEDICINE	TROUBLE BREATHING	THIRSTY	LIGHTS ON / OFF	CHAIR	NO VISITORS				
MOUTH CARE	BATHROOM	TIME / DAY?	TV ON / OFF	BED	GET THE LETTER BOARD						
MAYBE		DON'T KNOW		LATER							
MAYBE		DON'T KNOW		LATER							
1	2	3	4	5	6	7	8	9	0	YES	NO

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, Nursing Homes, and Home Life

- **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](#)
- Can also be accessed on a Mac or PC via [web browser](#)
- 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/connectioninthetimeofsocialdistancingpart2/>



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

- [WhatsApp](#)
- Requires a free WhatsApp account
- Free app for [iOS](#) and [Android](#)
- Free [desktop app](#) for Mac and PC

- [Snapchat](#)
- Requires a free Snapchat account
- Free app for [iOS](#) and [Android](#)

- [Skype](#)
- Internet calling



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

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Echo Show

- Hands-free video call with other Echo Show owners, or anyone who has the Alexa app on their smartphone
- The Echo Show can also cycle through your favorite photos — helping you feel close to your loved ones throughout the day
- All Echo devices can be used for an Alexa Drop In, which is a voice call option that operates similar to walkie-talkies, but between Echo devices in different homes





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 Wif-Fi range, like the garage or exterior of building, and finish the setup

- Source: https://ndassistive.org/blog/the-simplest-video-call-ever-no-touchscreen-for-covid-19/?utm_source=rss&utm_medium=rss&utm_campaign=the-simplest-video-call-ever-no-touchscreen-for-covid-19

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

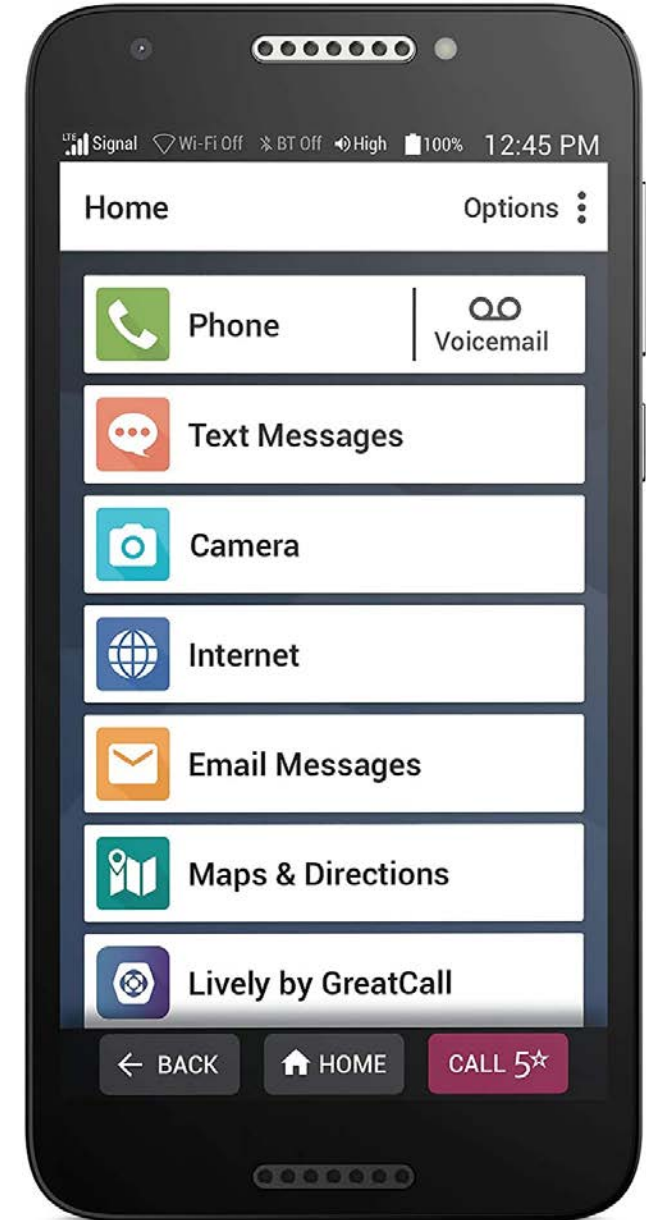
- The user can easily view family photos and videos, play games, see weather for each family member, listen to music, check emails, make phone calls, place a video chat, and much more
- Does not require Wifi
- Monthly bill (no yearly contract)
- \$40/month
- Currently out of stock so check website for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



HOLDERS



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)



fire HD10
OUR LARGEST
DISPLAY
— ON OUR —
THINNEST TABLET



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PC
PCMAG.COM

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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



Facebook Portal

- As Facebook's very own smart display, Facebook Portal can be used to video chat with your Facebook friends via Facebook Messenger
- While concerns of letting Facebook even deeper into our lives surfaced when Facebook Portal was first released, it's now considered one of the easiest smart displays to use for video chatting
- Since Facebook owns WhatsApp, you can also use your Facebook Portal to make and take WhatsApp video calls.

HANDS-ON
PORTAL
FROM FACEBOOK



Social Media

- Facebook
 - Groups allow you to connect with others
 - ALS – Patient and Caregiver tips for every day living
 - Our Lives with ALS
 - Veterans with ALS
 - ALS Assistive Technology Group
 - Chapter FB pages
 - Information, events, research, etc...
- Twitter
 - Great for advocacy
 - 249 character limit but you can do threads



ZOOM – it's more than just staring at your friends

- Movie nights
- Happy Hours
- Game nights
- Dinner
- Book Clubs
- Exercise
- Mindfulness
- Volunteer
- Visit exhibits, museums
- Paint / Art parties



Steam

- With more than 30,000 video games, 90 million active users and social features like friends lists and in-game message and voice chat capabilities, Steam is one of the best online gaming services
- With no subscription fee and online multiplayer games ranging from as little as \$5 to more than \$60, it's a great option for friends who want to play a game together
- Steam also offers Remote Play Together, which allows you to share a game you're playing at home with up to four friends remotely
 - This feature streams video, audio and voice between players, making it even easier to hop on and play with your friends.



Contact Information

- Alisa Brownlee
- abrownlee@alsa-national.org
- 215-631-1877
- Facebook: Alisa Brownlee ALS
- Twitter: [alsassistivetec](https://twitter.com/alsassistivetec)