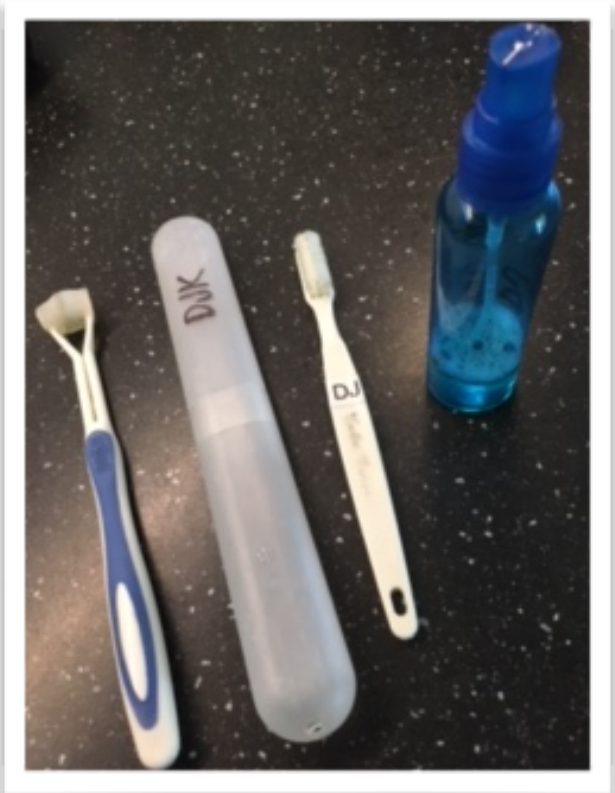
Making Dental Care and Visits Successful

My name is Donnell Kenworthy and I would like to share some things I have learned about getting dental care for my son. DJ, is 26 years old, has Down syndrome, autism, heart, lung and GI issues. He is G-Tube fed and silently aspirates, so he cannot eat by mouth. Getting good dental care for DJ has been a lot of trial and error, learning from other parents and professionals, making mistakes, keeping up with routines, rewarding positive growth and maintaining regular appointments for teeth cleaning under anesthesia.

He has had dental care with Dr. Rodney Bughao since he was 3 and sees him for cleaning about once a year to every 18 months.

Funding for my son's dental care has been a partnership with both Medi-Cal and Regional Center. I make sure that dental care needs are part of the goals in my son's IPP with Regional Center.

Through time we
have looked for
ways to make teeth brushing
successful for my son, DJ.
We have used a "three-sided"
toothbrush that we ordered
from Amazon.



Because DJ cannot rinse and
spit we use mouthwash in a
spray bottle on his toothbrush
instead of toothpaste.

Recently we have switched to a "Collis Curve" brush
(available on Amazon) that
appears to really reach
around the tooth and get at
the plaque and discoloration
at the base of his teeth.

Because of my son's aversion
to things in his mouth, and
his lack of find motor
dexterity, I still brush his
teeth, but I encourage more
and more independence.

How I Set up a Dental Cleaning Appointment:

1. **I contact my son's dentist's office and make appointment for his next dental cleaning. The time between set up and actual appointment may take some time, several weeks to months.**
2. **The dentist's office sends me paperwork to fill out and return. I return it promptly. I may need to make copies of important things like Medi-Cal card, conservatorship paperwork, etc. to send with the paperwork.**
3. **Sometimes my son's other doctors want to use the opportunity while he is sedated to take MRI scans, or get another procedure done. The hospital coordinates this but may need information from me and will call me.**
4. **I keep an easy to read but thorough document only computer that lists medical information about DJ. I make sure to update it regularly and often use it to answer questions from healthcare providers.**

I also make a copy to take with us to our dental cleaning appointment.

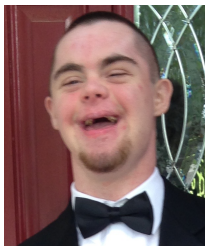
5. I pack items we will need and make sure I understand what protocols and equipment I need to bring. Does my son need to not eat? Should I bring his G-Tube extension? Is there last minute paperwork I need to take with me? Is my car all ready to go?
6. I make sure to pack myself snacks and a good book to read while waiting during his procedure. I plan for the time after we return home by not planning to do much other than see to my son's care. I may have an easy dinner planned.
7. On the day of the dental cleaning procedure, I go early so that we are both ready and don't feel rushed. I ask questions when I do not understand something and I make sure that the healthcare staff have DJ's paperwork.
8. During the procedure I wait in the waiting room and make sure Understand how I will be contacted when he is done.

9. **I remind myself to relax, take a deep breath, find gratitude for all the helpful people and find patience when things don't always go exactly as I felt it should.**
10. **Hospitals always call the day after a procedure and so if I have any concerns or reflections on what went well or poorly, I save it to share on that phone call.**

Some things I use to help dental cleaning appointments successful:

- **Social Story (a sample follows)**
- **Use rewards, like praise and time with a favorite toy**
- **Be prepared early and be cheerful throughout**
- **Be clear with Healthcare Providers about my questions and what make a visit successful for my son**
- **I make and use a "Medical History & Information" sheet that lists medications, doctors, phone numbers, etc. (Sample follows)**

Sample of Medical History & Information



MEDICAL INFORMATION FOR:

My Sonny One

nickname: Sonny

DOB: XX-XX-XXXX
birthplace: XXXXXXXX Hospital, XXXXXXXXXX, CA
parents: **Mom & Dad One**
address: 555 XXXXX St., Sacramento, CA
55555 (Sacramento County)

dad's cell: 555-555-5555 e-mail: XXXXXXXXXXXXXX@XXXXXXX.com
mom's cell: 555-555-5555 e-mail: XXXXXXXXXXXXXX@XXXXXXX.com

DIAGNOSES:

Down syndrome, autism, heart disease, G-Tube fed, GERD

ALLERGIES:

- Sulfa
- Milk

CURRENT MEDICATIONS:

- **Prevacid** 30mg solutab everyday
- **NutriSource** 2 Tblsps. BID in 60cc water
- **Miralax** 17gr:8oz. H2O 2-4 oz. daily
- **Zinc** 25 mg. ½ 50mg. capsule 1x daily

MEDICAL EQUIPMENT AND SUPPLIES IN THE HOME:

Convaid Wheelchair for longer distances, **Kangaroo Joey feeding pump, PerFit Pull on Briefs**, **iPad Communication device**, **prescription glasses**

DAY PROGRAM:

555-555-5555 XXXXXX Day Program
FAX 555-555-5555 1234 Happy Place
My Town, CA 55555

INSURANCE:

Med-iCal Yolo Co. 555-555-5555 Partnership Healthplan of CA
(providers) XXX-XXX-XXXX 123 This Road
Some City, CA 94585

REGIONAL CENTER:

Alta California Regional Center 555-555-5555 Sue Sweet, Serv. Coord.

PHARMACY:

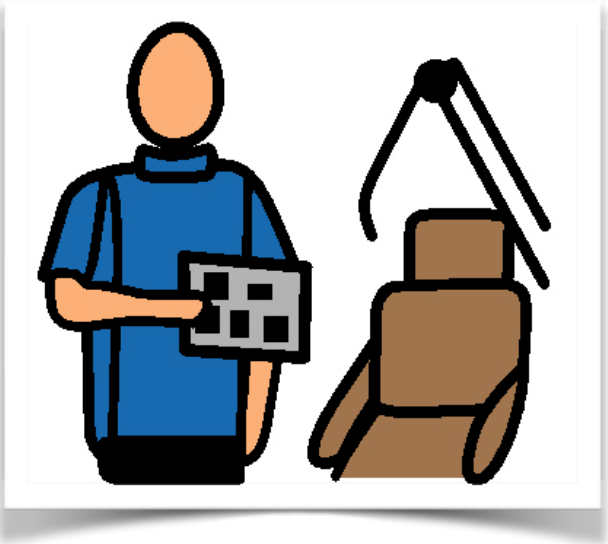
Rite Aid 555-555-5555 1234 Capitol Ave.
fax 555-555-5555 West Valley, CA 5555

CURRENT PHYSICIANS:

Primary:	Dr. L. Apple, M.D.	555-555-5555	1234 Hospital Lane Davis, CA 55555
	fax	555-555-5555	
Gastroenterologist:	Dr. O .Orange, M.D.	555-555-5555	1234 Hospital Lane Davis, CA 55555
	fax	555-555-5555	
Neurologist:	Dr. N. Cherry, M.D.	555-555-5555	1234 Hospital Lane Davis, CA 55555
	fax	555-555-5555	
Dentist:	Dr. B. Berry, DDS.	555-555-5555	1234 Smile Lane Davis, CA 55555
	fax	555-555-5555	

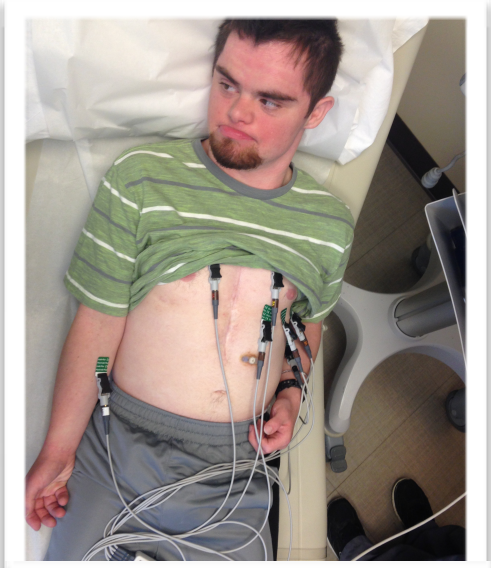
HISTORY & HOSPITALIZATIONS:

date	***place***	***outcomes [Surgeries in Bold]***
5/10 to 5/11/95	R Memorial Hosp. Small Town, CA	Born 16 days before due date significant oxygen requirement suspected heart defect **polycythemia-resolved by reduction exchange transfusion** transport to UCSF on 5/11/95
5/11 to 6/29/95	UCSF	transferred from Redwood Mem. Hosp., Fortuna, CA tested positive for Trisomy 21 **patent ductus arteriosus - ligated 5/15/95** **coarctation of aorta - repaired 5/15/95** phrenic nerve palsy and left diaphram paralysis following coarct repair **plication of left diaphragm - 5/24/95** heart catherterization - 6/8/95 **complete A/V canal defect - repaired 6/12/95** milk and soy allergy N/G tube fed breastmilk w/ Nutramigen added to increase calories discharged to home on oxygen -6/29/95
1/28 to 2/2/96	R Memorial Hosp.	Pneumonia and RSV severe diarrhea and desating spells (80% to 70%) transported to UCSF on 2/2/96
2/27/14	Sutter Memorial Hospital	Teeth cleaning under anesthesia
5/23/14	UCDMC	Dr. Orange,, start trial of Oxybutnin CL ER
9/17/14	Sutter Memorial Hosp	Dr.Goodfellow, order for Clindamycin, 1% topical soln.
10/3/14 Oxybutynin	UCDMC	Per Paula Wager, PNP with Dr. Orange, discontinue CL ER Due to vomiting. Start Oxybutynin patch (Oxytr



Sample Social Story

DJ is going to go see his dentist.



DJ will have monitors on his body.

DJ will take his favorite toy with him.

He may need to have
a breathing mask.
He will go to sleep.

Mom will be with
DJ.

DJ will wake up and
go home.
His teeth will be
clean.