



Prepare for Your Medical Care!

Documents to prepare patients with disabilities for medical visits

Print and keep these documents in a secure place. Fill out any blank forms with relevant information. In the event of a medical emergency or even a routine visit, we encourage you to bring them with you. The information may improve your interactions with healthcare providers.

Tip Sheet for Providers to Support Patients with Intellectual and Developmental Disabilities

The SUPPORT Tip Sheet is a one-page guide to inform healthcare providers on how they can support and accommodate patients with intellectual and developmental disabilities according to their preferences. It includes specific recommendations, identified by self-advocates and family members, to support patients who use augmentative and alternative communication (AAC).

Healthcare Passport

A healthcare passport tells providers about a patient's unique preferences, needs, and ways of communication in medical situations. It also includes their medical history, allergies, and current medications.

Plain Language Durable Healthcare Power of Attorney

A Durable Healthcare Power of Attorney allows an individual to choose a supporter, called an agent, to help them understand and make decisions for situations in healthcare. The agent may help make all or only certain health care decisions according to the person's expressed wishes. The agent also helps with obtaining informed consent.

Plain Language HIPAA Authorization Form

HIPAA, the Health Insurance Portability and Accountability Act, is a law that protects private medical information. With a HIPAA Authorization Form, a person can give a supporter the right to see their private medical information and discuss their medical care without the person in attendance.

Sample Pain Chart, Picture Board, and Letter Boards

For patients who use augmentative and alternative communication (AAC), we have attached a few sample communication boards that may support communication if customized devices are unavailable. We encourage you to search for assistive visuals that meet your individualized needs.

Contact Information for Supporters

This plain language contact sheet lists up to three supporters, their relationship to the patient, and their contact information in case of emergency.

California All Facilities Letter

The California All Facilities Letter authorizes the presence of a support person during the COVID-19 pandemic for patients with physical, intellectual, and/or developmental disabilities, and patients with cognitive impairments. Most healthcare providers are informed about this update to visitor guidelines, but we recommend bringing this document with you in case any issues arise.

Supported Decision-Making Agreement

A Supported Decision-Making (SDM) Agreement identifies chosen supporters in the areas where a person may want assistance, such as in health care decision-making. Uniquely tailored to the person, the SDM Agreement can be attached to legal documents, like powers of attorney, advanced medical directives and HIPAA authorization forms.

Personal Documents

We recommend that you also include a photocopy of the front and back of all insurance cards, identification cards, and driver's licenses. In addition, include any other personal documents that are critical to your care. For instance, you may want to add a mental health advance directive or living will.



SUPPORT

Patients with Intellectual and Developmental Disabilities in Emergency, Hospital, & Outpatient Care

SEEK INFORMATION

Ask about patient preferences for communication and care.* Many patients with Intellectual and Developmental Disabilities may converse using non-verbal gestures, or augmentative and alternative communication.

USE SUPPORTERS CHOSEN BY THE PATIENT**

Supporters can help obtain informed consent, discuss choices for care, and assist with the patient's decision-making. Chosen supporters may not always be present with the patient.

PRESUME COMPETENCE

Speak directly to the patient using a normal voice and plain language. Do not force eye contact—patients are still listening. Always ask patients or supporters if clarification is needed—do not make assumptions.

PROVIDE ACCOMMODATIONS

Be patient when time is needed to understand or use communication devices. Meet the patient where they are comfortable (e.g. some may sit on the floor or stay in the hallway). Provide a quiet, private environment with minimal distractions, when possible.

OBTAIN PERMISSION

Ask before making physical contact with patients—some do not like being touched. Explain what you are going to do before doing it, and check for understanding.

ROLE-PLAY WITH VISUALS

Use role-play with supporters to provide examples of treatment. Demonstrate on pictures, dolls, or the supporter.

TRAIN OTHERS

Share notes about accommodations, communication needs, and helpful strategies with the care team. Prepare new providers during shift changes. Ensure that patients and supporters understand discharge instructions.

*Patients may provide information in a health passport, one-page profile, or communication dictionary.

**Many states have issued guidance requiring health facilities to allow one support person for a patient with intellectual or developmental disabilities during the Covid-19 crisis.

This tip sheet was written by the self-advocates and family members of Disability Voices United, a California-based disability rights organization: disabilityvoicesunited.org.

H

My Health Passport

H



If you are a health care professional who will be helping me,

PLEASE READ THIS

before you try to help me with my care or treatment.



My full name is: _____

I like to be called: _____

Date of birth: ____ / ____ / ____

My primary care physician: _____

Physician's phone number: _____



This passport has important information so you can better support me when I visit/stay in your hospital or clinic.

Please keep this with my other notes, and where it may be easily referenced.

My signature: _____

Date completed: ____ / ____ / ____

You can talk to this person about my health: _____

Phone number: _____

Relationship: _____



I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)



My brief medical history: (include other conditions (e.g. visual impairment, hearing impairment, diabetes, epilepsy) past operations, illnesses, and other medical issues)



My current medications are:

- _____
- _____
- _____
- _____
- _____
- _____



When I take my medication, I prefer to take it: (e.g. with water, with food)



I am allergic to: (list medications or foods, e.g. penicillin, peanuts)



If I am in pain, I show it by: (also note if I have a low/high pain tolerance)



If I get upset or distressed, the best way you can help is by: (e.g. play my favorite music)



How I cope with medical procedures: (e.g. how I usually react to injections, IV's, physical examinations, x-rays, oxygen therapy—also note procedures never experienced before or in recent years)



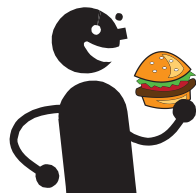
My mobility needs are:
(e.g. whether I can transfer independently, devices I use, pressure relief needed)



When getting washed and dressed, you may assist me by:



When drinking, you may assist me by:



When eating, you may assist me by:



My favorite foods and drinks are:



I do not like to eat or drink the following:



I am very sensitive to: (specific sights, sounds, odors, textures/fabric, etc. that I really dislike, e.g. fluorescent lights, thunderstorms, bleach, air freshener)



Things I like to do that will help pass the time:



How to make future/follow-up appointments easier for me:

(e.g. give me the first/last appointment of the day, allow extra time for the appointment, let me visit before my appointment, give information to my caregiver, etc.)

Durable Health Care Power of Attorney

(Plain Language Durable Power of Attorney for Health Care, adapted from the
ACLU Disability Rights Program, adapted from CA Probate Code § 4701)

Help Making Medical Choices

My name is _____

My birthday is _____

My address is _____

My agents

If I cannot make health choices for myself, I want someone to make choices for me. The person who will make these choices for me is called my agent.

My agents cannot be my doctor or someone who works in the hospital or a group home where I live.

My agent will only make choices for me if I cannot say what I want.

My agent's name is _____

Their phone number is: _____

Their address is _____

If I need help and my agent is away or cannot help me, another person can help me. This person is a back-up agent.

Backup agent's name: _____

Their phone number is: _____

Their address is _____

When my agent can help me:

- My agent can make choices for me if my doctor says that I cannot make my own choices.
- If the doctor thinks I cannot make my own choices, he or she must explain why in writing.

What my agent can do:

(Select everything you want the agent to be able to do for you.)

- My agent can make choices for me if I cannot make my own choices:
- My agent can choose what medicine I will get.
- My agent can see the notes doctors and nurses write about me.
- My agent can choose when I should stay in the hospital.

When my agent is making choices for me, my agent must do what I want. I will talk to my agent about what is important to me.

If my agent does not know what I want, he or she must make choices that will help me the most or talk to other people who love me and care about me.

I know that I have to sign this form with two people who are witnesses. My witnesses will sign on the next page.

I know that I can stop or change this agreement at any time.

My signature: _____

Today's date is: _____

THIS DOCUMENT MUST SIGNED BY TWO WITNESSES.

Certain individuals cannot serve as witnesses, as set forth in the following witness statements:

I declare under penalty of perjury under the laws of California

- (1) That the individual who signed or acknowledged this Power of Attorney for Health Care is personally known to me, or that the individual's identity was proven to me by convincing evidence.
- (2) That the individual signed or acknowledged this Power of Attorney for Health Care in my presence,
- (3) That the individual appears to be of sound mind and under no duress, fraud, or undue influence,
- (4) That I am not a person appointed as agent by this Power of Attorney for Health Care, and
- (5) That I am not the individual's health care provider, an employee of the individual's health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

First Witness

Name _____
 Address: _____
 City/State: _____
 Signature: _____
 Date: _____

Second Witness

Name _____
 Address: _____
 City/State: _____
 Signature: _____
 Date: _____

ONE OF THE PRECEDING WITNESSES ALSO MUST SIGN THE FOLLOWING DECLARATION:

I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of the individual's estate upon his or her death under a will now existing or by operations of law.

Signature: _____

Date: _____

IF THE PERSON MAKING THIS POWER OF ATTORNEY IS UNABLE TO WRITE, BOTH WITNESSES MUST SIGN THE FOLLOWING DECLARATION:

_____, being unable to write, made his/her mark in our presence and requested the first of the undersigned to write his/her name, which he/she did, and we now subscribe our names as witnesses thereto.

Signature of Witness #1: _____

Signature of Witness #1: _____

IF THE PERSON MAKING THIS POWER OF ATTORNEY LIVES IN A NURSING HOME, THIS SECTION MUST BE COMPLETED BY THE PATIENT ADVOCATE OR OMBUDSMAN:

I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by Section 4675 of the Probate Code:

Name _____

Address: _____

City/State: _____

Signature: _____

Date: _____

HIPAA Authorization

(Plain Language HIPAA Authorization for Disclosure of Health Information, adapted from the ACLU)

Sharing My Medical Information

My name is _____

My doctor's office
or hospital is called: _____

It is in this city: _____

My doctors and nurses write notes about me. They also write about the tests they do. These notes are called records. I want to share my medical records.

The person who can see my records is:

Name: _____

Address: _____

Phone number: _____

Email address: _____

This person can see: *(Select one)*

All of my medical records.

Only some records. The records this person can see are:
(Write what records you want the person to see.)

This person can see my records until: *(Select one)*

This date: _____.

When I sign a form to say that this person can no longer see my records.

I know these records are usually kept private. I have chosen to share them with the supporter I named above.

My doctors and nurses have to be very careful with my medical records. They cannot usually show my records to other people. The person who I am sharing my records with cannot share them with other people unless I agree. I trust the person I am sharing my records with.

I know that I can stop this agreement at any time.

My signature: _____

Today's date is: _____

Pain Chart

Pain Level

10

9

8

7

6

5

4

3

2

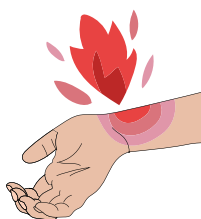
1



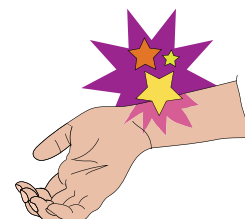
itches



hurts



burns



stings



headache



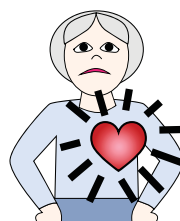
ear ache



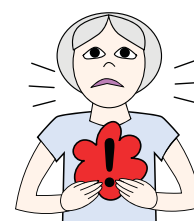
sore throat





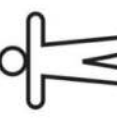







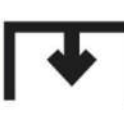





back pain



heart pounding



upset stomach

question 	afraid 	sad 	funny 	happy 	hurt 	sick 	mad 	body 	good 
time/now 	l/me/my 	want 	make 	ride 	have 	thing 	gone 	together 	more 
late/earlier 	here 	home/place 	eat/drink 	work 	open 	get 	all 	same 	thought/idea 
early/earlier 	it 	can/do 	go 	help 	close 	put 	in 	different 	on 
wait 	you/your 	like/love 	turn 	play 	read 	wash/clean 	out 	up 	off 
yes 	maybe 	no 	to 	buy/pay 	tell/say 	listen 	watch/see 	down 	stop 
COVID-19 	medicine 	doctor/nurse 	testing 	headache 	cough 	breathe 	away 	hot 	bathroom 



800-204-7428 V
866-268-0579 TTY
TechOWL@temple.edu



Q	W	E	R	T	Y	U	I	O	P
---	---	---	---	---	---	---	---	---	---



A	S	D	F	G	H	J	K	L
---	---	---	---	---	---	---	---	---

Z	X	C	V	B	N	M
---	---	---	---	---	---	---

1	2	3	4	5	6	7	8	9	0
---	---	---	---	---	---	---	---	---	---



800-204-7428 V
866-268-0579 TTY
TechOWL@temple.edu
TechOWLpa.org

A	B	C	D	SPACE	END OF MESSAGE	I'M HAVING TROUBLE BREATHING.
E	F	G	H	START OVER	I DON'T KNOW	WHAT WILL HAPPEN NEXT?
I	J	K	L	M	N	WILL I GET BETTER?
O	P	Q_u	R	S	T	WHAT ARE MY OPTIONS?
U	V	W	X	Y	Z	I WANT TO DISCUSS MY OPTIONS.
1	2	3	4	5	6	I HAVE ANOTHER QUESTION.
	7	8	9	∅	YES 	NO 

A

B

C

D

.

Start
Again

E

F

G

H

Space

Ask
yes/no

I

J

K

L

M

N

O

P

Q

R

S

T

U

V

W

X

Y

Z

Communication Board

This communication board is to be used with individuals who do not have the ability to point and their eye use is poor. You are setting up a system where you, the Communication Partner (CP), ask a question to organize the communication and the communicator must be able to respond with an “affirmative” or “negative”

You first list through the colors. The communicator will need to confirm “affirmative/yes” when you say the color of the intended letter.

“ gray” “blue” “yellow” “pink” “green”

Once the row is determined the CP lists from left to right the letters/message in that row. The communicator will confirm “affirmative/yes” on their desired letter/message.

Repeat this sequence until the message is complete.

Emergency Contacts

This is a list of the people that support me. If I require assistance, please contact:

Contact Information	
Supporter #1	
Name:	_____
Relationship:	_____
Home Phone:	_____
Work Phone:	_____
Cellphone:	_____
Fax No.:	_____
Supporter #2	
Name:	_____
Relationship:	_____
Home Phone:	_____
Work Phone:	_____
Cellphone:	_____
Fax No.:	_____
Supporter #3	
Name:	_____
Relationship:	_____
Home Phone:	_____
Work Phone:	_____
Cellphone:	_____
Fax No.:	_____



State of California—Health and Human
Services Agency
**California Department of
Public Health**



August 7, 2020

AFL 20-38.4

TO: All Facilities

SUBJECT: Visitor Limitations Guidance
(This AFL supersedes AFL 20-38.3)

All Facilities Letter (AFL) Summary

- This AFL notifies all facilities of updated visitor guidelines for pediatric patients, patients in labor and delivery, neonatal intensive care unit (NICU) patients, pediatric intensive care unit patients (PICU) patients, and patients at end-of-life and patients with physical, intellectual, and/or developmental disabilities and patients with cognitive impairments.
- Health facilities may permit a support person to accompany a patient for whom a support person has been determined to be essential to the care of the patient (medically necessary), including patients with physical, intellectual, and/or developmental disabilities and patients with cognitive impairments.
- This AFL has been updated to clarify that long-term care facilities and hospitals may permit students obtaining their clinical experience into the facility if they meet the CDC guidelines for healthcare workers. This revision also clarifies when a doula may be permitted during labor and delivery.

Due to the community spread of Coronavirus Disease 2019 (COVID-19), considerations must be made for the safety of health facility staff and patients, resulting in many health care facilities suspending visitation, except when medically necessary or essential to the care of the patient. The California Department of Public Health (CDPH) recognizes the importance that visitors play in the mental well-being of patients, including pediatric patients, NICU and PICU patients, patients in labor and delivery, and patients at end-of-life. CDPH also recognizes the importance of ensuring people with disabilities receive the support they need while hospitalized. CDPH considers visitors an essential part of patient care and recovery.

CDPH has developed recommended visitor guidelines for certain patients to ensure support for their mental health and well-being, while striving to limit the spread of the virus.

Pediatric Patients

- Visitors are essential for the mental health of pediatric patients. CDPH recommends that pediatric patients be allowed one support person.
- In the case of prolonged hospitalization, CDPH recommends two designated support persons for pediatric patients, provided that only one visitor is present at a time.
- For NICU and PICU patients, CDPH recommends two designated support persons that may visit at the same time.

Labor and Delivery Patients

- The presence of a partner or support person is essential to the mental health of patients who are in labor and delivery. CDPH recommends that one support person be allowed to be present with the patient. CDPH also recommends that a doula, if used, be permitted to be present if prior arrangements have been made with the hospital and the doula complies with hospital PPE and infection control guidelines.

Patients at End-of-Life

- Visitors are essential to the mental health of patients who are at end-of-life. For their continued mental health, and well-being, the department recommends that one visitor be allowed to be present with the patient.

Patients with Physical, Intellectual, and/or Developmental Disabilities and Patients Cognitive Impairments

- The presence of a support person is essential to patients with physical, intellectual, and/or developmental disabilities and patients with cognitive impairments. CDPH recommends that one support person be allowed to be present with the patient when medically necessary.
- For hospitalized patients, especially with prolonged hospitalization, the patient or family/patient representative may designate two support people, but only one support person may be present at a time.

Students Obtaining Clinical Experience

- CDPH supports efforts to help ensure that new nurses and other professionals coming into the healthcare workforce are able to obtain necessary clinical experience. CDPH encourages students obtaining their clinical experience be permitted to come into the facility if they meet the CDC guidelines for healthcare workers to maintain the workforce needed during this pandemic.

All support persons must stay in the room and be asymptomatic for COVID-19 and not be a suspected or recently confirmed case. Support persons may be screened prior to entering clinical areas. Support persons must comply with any health facility instructions on personal protective equipment.

Additionally, CDPH strongly encourages facilities, including but not limited to skilled nursing facilities, to create ways for residents and patients to have frequent video and phone call visits. If shared devices are used for video calls facilities should ensure appropriate infection control measures are in place.

If you have any questions about this AFL, please contact your local district office.

Sincerely,

Original signed by Heidi W. Steinecker

Heidi W. Steinecker
Deputy Director

Resources
CDC Guidelines

Center for Health Care Quality, MS 0512 . P.O. Box 997377 . Sacramento, CA
95899-7377

(916) 324-6630 . (916) 324-4820 FAX
Department Website (cdph.ca.gov)



Supported Decision-Making Agreement

Adapted from the ACLU Disability Rights Program Supported Decision-Making Agreement

This agreement must be read out loud or otherwise communicated to all parties to the agreement in the presence of either a notary or two witnesses. The form of communication shall be appropriate to the needs and preferences of the person with a disability.

My name is: _____

I want to have people I trust help me make decisions. The people who will help me are called supporters. I know that I can rely on my supporters to offer information and discuss options and choices with me.

I make decisions about my life, with support.

This agreement can be changed at any time. I can change it by crossing out words and writing my initials next to the changes. Or I can change it by writing new information on another piece of paper, signing that paper, and attaching it to this agreement.

These are my supporters:

(If you have more than three, just list the first three)

Supporter's name: _____

Supporter's name: _____

Supporter's name: _____

This is my monitor:

Monitor's name: _____

My supporters can talk to each other about me: *(Check one box.)*

Only when I say it is OK

Whenever they want

Meeting with my support team

I can talk to my supporters anytime I want to. But my whole team might meet together sometimes to talk about how we are doing. (Check one box:)

I want my entire support team to meet _____
(Write how often your whole team will meet, like "every week" or "every two months" or "before every IPP meeting".)

I do not want my support team to meet on a regular basis.

Special directions and other information

I can write any other information or special directions here. I can also write more information on a separate piece of paper and attach it to this agreement. For instance, I may communicate here through the use of a visual system or format unique to me.

I am signing this supported decision-making agreement because I want people to help me make choices. No one is making me sign this agreement. I know that I can change this agreement at any time.

This supported decision-making agreement starts right now and will continue until the agreement is stopped by me or my supporters.

My printed name: _____

My address: _____

My phone number: _____

My email address: _____

Wait to sign your name until a notary or two witnesses are there to watch you sign.

My signature: _____

Today's date is: _____

My Supporter

(This page can be duplicated for as many supporters as you want to sign the agreement)

Supporter's name: _____

Their address: _____

Their phone number: _____

Their email address: _____

I want this person to help me with these choices:

(check as many boxes as you want)

Personal Care:

- Making choices about food
- Making choices about clothing
- Taking care of personal hygiene (showering, bathing)
- Remembering to take medicine Staying Safe:
- Making safe choices around the house
(for example, fire alarms, turning stove off)
- Understanding and getting help if I am being treated badly (abused)
- Making choices about alcohol and drugs

Home, Work, and Friends:

- Making choices about where I live and who I live with
- Making choices about where to work or what activities to go to
- Choosing what to do in my free time
- Finding support services, hiring and firing staff

Health Choices:

- Choosing when to go to the doctor or dentist
- Making medical choices for everyday things
(for example, check-up, small injury, taking aspirin)
- Making choices about major medical care
(for example, big injuries, surgery)
- Making choices about medical care in emergencies

Partners:

- Making choices about dating, sex, birth control, and pregnancy
- Making choices about marriage

Money:

- Paying the bills on time and keeping a budget
- Keeping track of my money and making sure no one steals my money
- Making big decisions about money (for example,
opening a bank account, signing a lease)

Other:

(Write any other areas where you want support from this person):

- _____
- _____
- _____

My Monitor

If I want someone to help me make choices about money, I can also choose someone to make sure my supporters are being honest and using good judgment in helping me with my money. This person is called a monitor. The monitor should not be a supporter.

I do not have to write anything here if I am not asking anyone to help me with money. I do not have to write anything here if I do not want a monitor.

Monitor's name: _____

Their address: _____

Their phone number: _____

Their email address: _____

Consent of Supporter

I, _____, consent to act as _____'s supporter under this agreement. I understand that my job as a supporter is to honor and express his/her/their wishes. My support might include giving this person information in a way he/she/they can understand; discussing pros and cons of decisions; and helping this person communicate his/her/their choice. I know that I may not make decisions for this person, unless he/she/they ask(s) me to decide. I agree to support this person's decisions to the best of my ability, honestly, and in good faith.

Signature of supporter: _____

Date: _____

Consent of Monitor

I, _____, consent to act as a monitor for _____'s financial decisions under this agreement. I agree to review the financial records of the person with a disability when provided by the supporters at least every quarter. I agree to make reasonable efforts to ensure that the supporters under this agreement are acting honestly, in good faith, and in accordance with the choices of the person with a disability. If I suspect financial abuse, misuse of funds, bad faith, or failure to comply with the decisions of the person with a disability, I will require the supporters to explain their actions. If the supporter fails to provide this information or if I continue to have reason to believe that the supporter is abusing or failing to comply with the wishes of the person with a disability, I will promptly inform Adult Protective Services.

Signature of monitor: _____

Date: _____

Seal of notary:

My commission expires: _____

Signature of Notary or Witnesses

*This document must be read in front of either a notary or two witnesses.
Witnesses may not include supporters, monitor, or the person with a disability.*

Signature of Notary

State of California, County of _____

On _____ (date), before me _____ (name of person with a disability),

personally appeared, along with _____

(names of all signers), who proved to me on the basis of satisfactory evidence of identification to be the people whose names are signed on this Supported Decision-Making agreement.

The text of this agreement was communicated to the person with a disability in my presence by:

Reading the full agreement aloud

Otherwise communicating the agreement to the person with a disability

(describe communication used): _____

Seal of notary:

My commission expires: _____

or

Signature of Witnesses

I, _____, swear that this Supported Decision-Making Agreement was communicated in my presence to the person with a disability.

Signature: _____ Date: _____

I, _____, swear that this Supported Decision-Making Agreement was communicated in my presence to the person with a disability.

Signature: _____ Date: _____

DISABILITY VOICES UNITED

Together We
Will Be Heard

We need your voice.

We are stronger together than we are alone. By supporting Disability Voices United, you send a clear message that you, too, want to improve regional centers and education — and you want major changes now for people with developmental disabilities.

To learn more about our work and opportunities to get involved, visit

DisabilityVoicesUnited.org

 Disability Voices United

 @DVoicesUnited

530-JOINDVU (530-564-6388)
info@dvunited.org

Mailing address only:
1230 Rosecrans Ave, Suite 650
Manhattan Beach, CA 90266