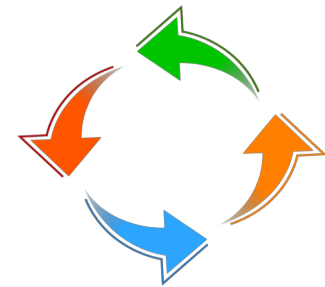


THE FAMILY EXPERIENCE
FROM *PARENTS FOREVER* FAMILIES
RE: OPIOID AGONIST THERAPIES

CLOSING CONGRESS BOOST COLLABORATIVE
DECEMBER, 2018



**SUMMARY OF FEEDBACK FROM *PARENTS FOREVER* FAMILIES
RE: OPIOID AGONIST THERAPIES
DECEMBER, 2018**

***PARENTS FOREVER* – A “REFRESHER”**

For the **past 18 years**, *PARENTS FOREVER* has been providing an **ongoing, mutual support group for parents and family members** of loved ones struggling with substance use.

PARENTS FOREVER has a membership of over **350 people** who receive communication on a regular basis – notice of meetings, speakers, special events, new resources, etc.

Meetings are held every second Friday, with an **average of 20 people** in attendance.

Parents and family members **receive emotional support** as well as a **new toolbox of coping skills and strategies**.

The group is **professionally and financially supported** and is **managed by the Boys and Girls Clubs of South Coast BC**

In June of this year, Fraser Health contracted *PARENTS FOREVER* to do a weekly group in **Surrey**.



RESULTS FROM A SURVEY CONDUCTED WITH 20 PARENTS FOREVER PARENTS AND FAMILY MEMBERS, NOVEMBER 2018:

How long a period of time has your loved one been taking methadone, suboxone, kadian, etc.

A. Ranged from 5 weeks to three years...with the **highest number being 3 years**

Did your loved one experience any side effects from taking this medication?

A. **90% reported Yes** to this question, with the following being the most common side effects:

Sleeplessness

Depression

Weight gain

Unable to feel joy...feeling numb

Constipation

Were you able to get information you need in order to support your child, i.e. meetings with physicians, clinicians, others?

A. Response was **split down the middle between Yes and No.**



**SUMMARY OF FEEDBACK FROM *PARENTS FOREVER* FAMILIES
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What were the roadblocks you encountered trying to get the information and what can be done to improve it?

Roadblocks:

Methadone doctors are inaccessible to family members

No formal communication or support for parents of young adults – over 17

Not able to speak to any professional at clinic son was attending

No information on how or when to taper off

Suggested Improvements

A team (or team member) should be in place to talk to family members who are trying to support their loved one

Families should be able to provide collateral information without endangering **confidentiality***

Family members need to be included in the “circle of care” as they are with many other medical conditions

*refer to **VCH's Family Involvement with Mental Health and Addiction Policy:**

http://mentalhealth-policies.vch.ca/CA_4200.pdf



**SUMMARY OF FEEDBACK FROM PARENTS FOREVER FAMILIES
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From your point of view what are the benefits of your loved one being on these medications?

Helped my child get and stay sober. Reduced cravings. Life saving treatment

Patient is able to function “normally” for the most part on methadone

Not exposed to Fentanyl

Able to complete a residential program and stay sober for 10 months

Methadone saved son's life and allowed him to get off the streets and into recovery

Increased stability from repeated relapses

Combination of Suboxone and an anti-anxiety medication has provided a stable base free from opioid addiction for two years, attending school, living independently etc.

Family members free from the anxiety of loved one using street drugs

Comfort and strength in having a routine – going to pharmacy and managing schedule around medications.

Cravings satisfied in a safe manner

Safer and more stable



**SUMMARY OF FEEDBACK FROM *PARENTS FOREVER* FAMILIES
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What were the DOWNSIDES?

Schedule (work, school, etc.) impacted by need for pharmacist's witness on oral med.

When seeking employment or working must try to access late night services and doesn't dare allow employer know due to perceived stigma.

Social stigma of opioid agonist medications

Suboxone not available in BC in a pill form less than 2 mg, making reducing off drug difficult

Physicians and staff at clinics not explaining downside of opioid agonist treatment

Inability to travel outside Canada because drug carries not available for long periods of time

Naltrexone not available in injectable form in BC – very expensive in Bellingham

Very difficult to wean off methadone etc – support not provided

Average age of a methadone user is only 39????

It appears that there is a lack of continuance of services to become drug-free with a perception that the transition to substitution drugs has somehow removed the chains of drug dependency.

Many treatment facilities & programs do not accept or allow patients who were on medication



**SUMMARY OF FEEDBACK FROM PARENTS FOREVER FAMILIES
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Comments:

We the parents feel Kadian is literally a lifesaver. However drugs are only part of the treatment program and we have a role – emotional, financial and logistical – but there are no resources for us to participate in that role. There is no support for counselling therapy, nor for parents to act as advocates when a crisis arises

Son who is sober misses social life – partying, girlfriends...used drugs to overcome shyness.

Loved ones who are admitted to detention have to wait a full week for their suboxone because the medication delivery is once a week and they arrived after the medical staff had been there. This can force them into detox without proper medical support

Would love to hear of a path beyond substitution drug therapy, with a compassionate method to withdraw from long term effects of methadone

Believe patients would stay on medication if there was a shorter time frame to get onto the suboxone carry program.

Methadone and Suboxone are very effective at creating temporary stability from relapse and a sense of safety from overdose. Side effects are hard to manage so people want to get off the medication.



SUMMARY OF FEEDBACK FROM BOOST COLLABORATIVE TEAM MEMBERS

RE: FAMILY INVOLVEMENT

DECEMBER, 2018

Received from the START Program:

We understand that families can be strength in treatment and the recovery journey but they can also cause *barriers and challenges**

They need education and need to be involved during the treatment and lots of hand-holding and support.

Staff understands how to separate help from tension

Families can offer motivation, strength, support, financial resources, transportation, etc.

* *Barriers and challenges* identified as:

Family wanting to control the process, creating power struggle

Family believing they know everything and how the client is feeling and experiencing

Family need to direct the care

Family withdrawing financial assistance during the detox process

Family thinking: My way or No way

Family's knowledge and understanding about detox

Family's personal health and well being



MOVING FORWARD POST-BOOST COLLABORATIVE FAMILIES & SERVICE PROVIDERS

Finding ways to improve and maintain communication between families and service providers. This may include:

Convening a panel discussion with family members and service providers to discuss openly and frankly the barriers and challenges (see previous slide) to the sharing of information and involvement in treatment that can be improved. This could take place in a “mini-forum” setting. Parents Forever would be happy to arrange this.

As a follow-up to this, a sub-committee could be formed to meet a couple of times a year (informally) to bring any issues forward that may be of concern to either group.

As noted from the feedback received from families included in this presentation, Parents Forever members are very eager to find ways of making the experience of taking opioid agonist medications better for their loved ones.



**MOVING FORWARD
POST-BOOST COLLABORATIVE
FAMILIES & SERVICE PROVIDERS**

SUGGESTIONS WELCOME!!!!

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