

Breaking Bad News

Disclosing Illness and Death to Children in the Covid Crisis

20th May, 2021

SAMVAD

**Support, Advocacy & Mental health
interventions for children
in Vulnerable circumstances And
Distress**

**(A National Initiative & Integrated
Resource for Child Protection, Mental
Health, & Psychosocial Care)
Dept. of Child and Adolescent
Psychiatry**

**National Institute of Mental Health &
Neurosciences (NIMHANS), Bangalore
Supported by Ministry of Women &
Child Development, Government of
India**



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Breaking Bad News

Disclosing Illness and Death to Children
in the Covid Crisis

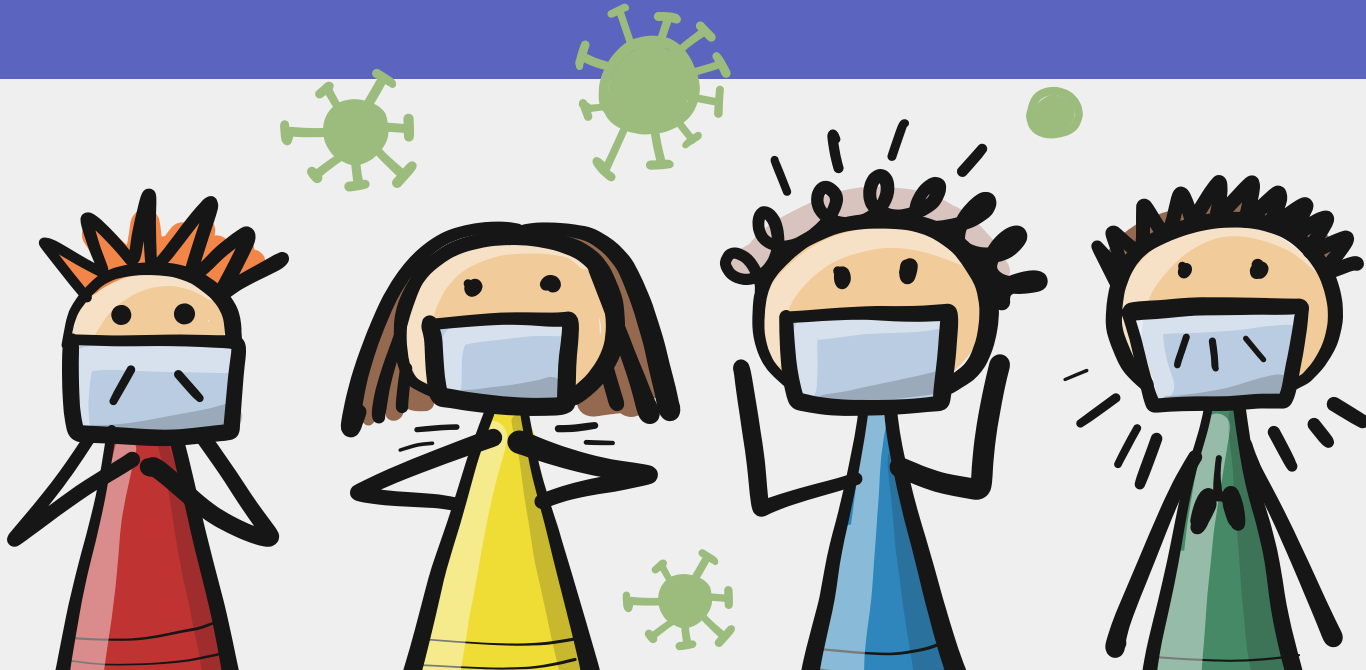
**Thursday, 20th May 2021
5:30-8:00PM**

OBJECTIVES

Why should we talk about illness to children ?

What illness disclosure is about (in context of Covid-19) ?

How to disclose illness of Parent/ Caregiver to a child ?



Severity of Virus -
HIGH

Levels of
Infectiousness and
Spread -
HIGH

Mortality Rate -
HIGH

Burden on Public
Health System-
HIGH

NEWS18

Latest Coronavirus Movie IPL 2021 Photos Buzz Politics

NEWS18/NEWS/INDIA/WITH CHILDREN BECOMING ORPHANS DUE TO COVID, NGO'S & CARE CENTERS STRUGGLE TO KEEP THEM SAFE

With Children Becoming Orphans Due to Covid, NGO's & Care Centers Struggle to Keep Them Safe



Image for representation.

indiatoday.in

News / Coronavirus Outbreak /

Covid-19 second wave leaves many children orphaned and vulnerable across India

While some have lost both their parents, others are in a situation where a single surviving parent is unable to take care of them financially and psychologically.



SBS News




A file photo of an orphan at Balgran charitable Orphanage home in Jammu, India, 24 April 2020. Source: EPA

COVID is leaving hundreds of Indian children orphaned. Now there are concerns of child trafficking

India's COVID crisis has left a wave of new orphans to fend for themselves, and

COVID is leaving kids orphaned but adoption pleas are illegal

Mohua Das | TNN | May 10, 2021, 04:52 IST



Representative image

Get Notifications on latest India News

In the midst of cries for oxygen, hospital beds and emergency drugs on social media, a desperate appeal from people in

OPEN IN APP

HEIGHTENED VULNERABILITIES AND NEW IMPLICATIONS

- **Parents/ Caregivers/ Family members falling sick due to Covid Disease**
- **Children confused, unsettled, struggle to make sense of the chaos often.**
- **Adults remain preoccupied with their own upset, the administrative formalities , last minute arrangements ignoring children and their worries.**
- **Stories of young children left on their own ... to fend for themselves.**
- **Children overhear conversations about the death from neighbors or relatives and deal with overwhelming fear about their own and their parent/ caregiver's wellbeing**
- **Children at risk of emotional and behavioral problems as the feelings bottle up, confusions and fears rise.**



LET US NOW CHECK SOME MYTHS AND FACTS ABOUT DISCLOSING ILLNESS

FACTS

~~MYTHS~~

HOW DO WE USUALLY RESPOND TO THESE WORRIES?



| | |
|------------------------------|---|
| Diversion | <i>" Mumma and Papa are going to the market to get you some gifts "</i> |
| | <i>"Your parents will definitely get better. Don't worry."</i> |
| Absolute | <i>"Just pray to God... no one knows what will happen ...I am just so worried about you."</i> |
| | <i>"Don't cry everything will be okay."</i> |
| Assurances | <i>"Leave all the worries to us, you don't worry about anything..."</i> |
| Avoidance | <i>"You see how difficult things are? Please be quiet and we are tired."</i> |
| | <i>"You are not a so young anymore...please be a little more responsible...don't create more problems "</i> |
| Complete Hopelessness | <i>"No one knows, your father may die also "</i> |

BARRIERS TO DISCLOSURE

- **It makes us feel uncomfortable ...we don't know what to say.**
- **We feel scared because we do not have the answers**
- **We assume children will not understand**
- **We feel protective and we want to save children from being upset**
- **We make predictions regarding children's reactions and feel being silent would be the best way to avoid dealing with their emotional upset.**
- **We fear it might further trigger them.**



REMEMBER ...

Children are curious.

They have questions.

They want to know.

They need to know.

They have the right to know.

PRINCIPLES OF DISCLOSURE

- **Do not make it a one off event**
- **Be age appropriate**
- **Tell the truth, no lies**
- **Give hope and reassurance**

**LET US CRITICALLY EXAMINE SOME
CASES.**



**UNDERSTANDING THE NEED FOR
DISCLOSURE**

Lulu is a 7 year old, her parents are both hospitalized due to COVID. She is living with her grandparents. She has not been told about her parents, she was told that they had gone away for a business trip.

Recently she has been asking her grandparents how long it will take for them to come back. She has asked her grandfather to call her parents to talk to them.

She has been clingy and crying asking for her parents, she looks outside everyday to see if her parents are coming. Her grandparents are confused as to how to break the news to the child.

**What will be some of the
Questions, Confusions and
Thoughts in Lulu's mind?**

Why am I not allowed to see my parents?

I want to go back home.

I want to eat food cooked by my mother

Where are my parents?

*Will my parents never
come back?*



*I want to go out with my
parents*

I miss my parents

Lulu's Thoughts

What if grandparents are lying?

When will my parents come back ?

13 year old Panna's mother was infected with the virus. In a few days, Panna's mother's infection got worse and she sent Panna away to her friend's house. Panna was writing her online exam when she was told that her mother had to be taken to the hospital.

**Panna talks to her mother over phone everyday . Her mother says ,
"I will be home soon. I miss you"
Its already been 16 days.**

Panna's aunt tells her not to worry.

Panna does not like the aunt's place, her kids are too loud and she feels its very insensitive of them to always be loud and noisy when she is so worried.

**What will be some of the
Questions, Confusions and
Thoughts in
Panna's mind?**

Will my mother die?

I wish I were sick instead of my mother

*I hate my aunt and her kids they
are so insensitive*

I want to go home

What will I do without my mother?



*If I were old I would have
taken care of her*

what if I never see her again

Panna's Thoughts

16 year old Meeta lives in a Child Care Institution. She was placed in the institution after the death of her mother almost one year ago.

One day, Meeta receives a call from a hospital saying that the father is critically ill due to the Covid-19 illness and she is urgently required to be with him at the hospital.

Meeta goes to the hospital and is now asked to contact the family. She calls up the counsellor of the Child Care Institution.

Her father's organs have started to fail and his health is critical. Meeta is now back in the Child Care Institution.

**What will be some of the
Questions, Confusions and
Thoughts in Meeta's mind?**

Why is this happening to me?

I don't want to talk to anyone

I wish I was out of this institution

No one understands me

Why is God so cruel?

I don't want to lose my father

How can I be with my father?



What should I do?

Meeta's Thoughts

15 year old Raghu's mother is worried about his father . His father has been in the hospital for the last 4 days. She cries often . Whenever Raghu asks her she tears up. He has been continuously asking when will father come back.

He has overheard his mother's conversations with the relatives. He has heard in the news that the second wave is scarier than the first one. He watches YouTube footages all day. He is worried.

He has been acting "responsibly" with "maturity". His grandmother told him over the phone that everything will be okay...he is the man in the family and he should take care of his mother and not upset her by asking too many questions.

**What will be some of the
Questions, Confusions and
Thoughts in Raghu's mind?**

I hope this virus goes away

Why is no one telling me what has happened ?

What if something happens to my mother?

Will we all die?

I have to take care of my mom now



I hope my father comes back

*Uncle Manoj died after
they took him to the hospital ...*

Raghu's Thoughts

Who will take care of us now?

WHY IS IT IMPORTANT TO MAKE DISCLOSURE?

- **Unprocessed interactions , silences and diversionary methods worsen anxieties**
- **The Negative thoughts become louder generating difficult emotions**
- **Half answers , brief responses confuse children feed into their negative thoughts, thus processing experiences to generate meanings that lead to several misconceptions and fears**
- **Generalized sweeping responses make children feel hopeless and less reassured**
- **Children build personal narratives about the loss event, based on their observations and what they overhear from neighbors, relatives , news.**

**HOW SHOULD WE THEN TALK ABOUT ILLNESS
AND MAKE DISCLOSURE ABOUT PARENT/
CAREGIVER'S ILLNESS TO THE CHILD ?**

When Spots Went Away



**WHAT KIND OF QUESTIONS CAN WE ASK TO
CHILDREN BASED ON THE STORY- WHEN
SPOTS WENT AWAY?**

DISCUSSION

- **Who was Spots?**
- **Why was Spots so special to Tariq?**
- **How did Tariq feel when Spots went away?**
- **What happened to Spots?**
- **Do you think Tariq loved Spots and took care of him?**
- **Do you think Spots went away because of Tariq?**
- **What did Tariq's parents tell him when he was worrying about Goldie losing Spots?**
- **How did Tariq deal with the sadness?**
- **Did Tariq feel better in the end?**

A STEP-WISE GUIDE TO DISCLOSURE DEVELOPING RESPONSE SCRIPTS

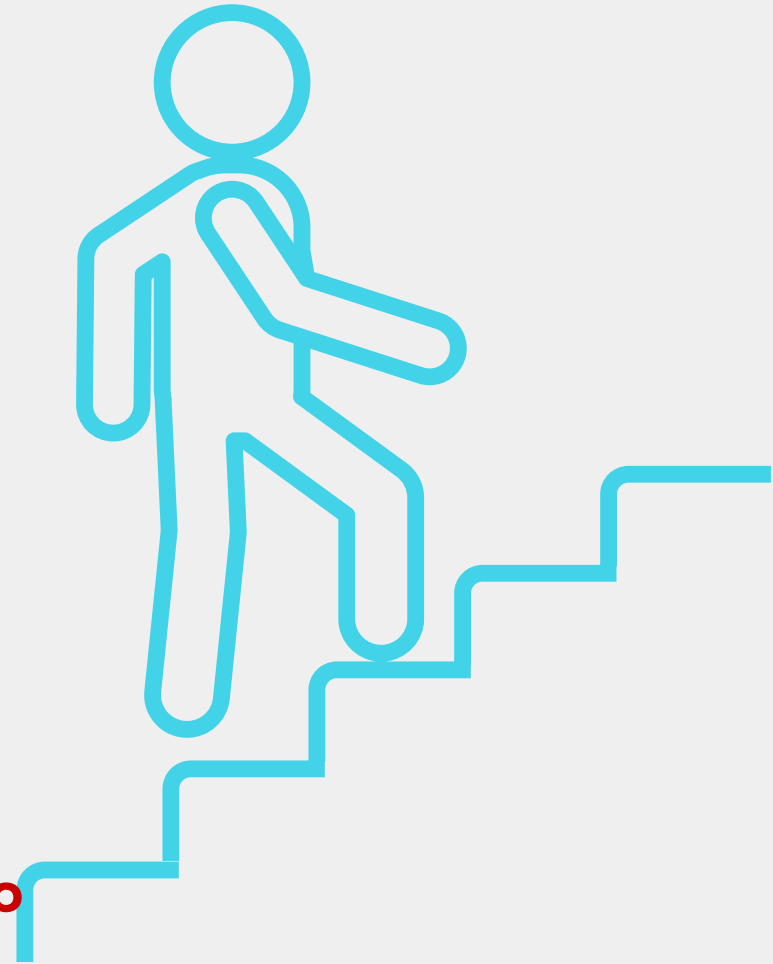
**STEP 1 Building Perspective on Health
and Safety**

**STEP 2 Explaining Big and Small
sicknesses**

STEP 3 Explaining Covid as a Sickness

**STEP 4 Providing Reassurance and
Hope**

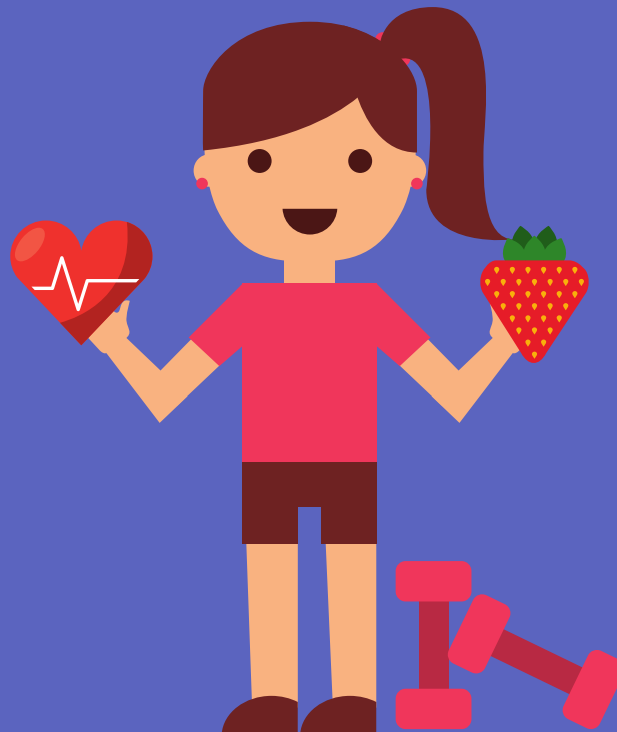
**STEP 5 Encouraging and Responding to
Additional Questions**



STEP -1



HEALTH AND SICKNESS



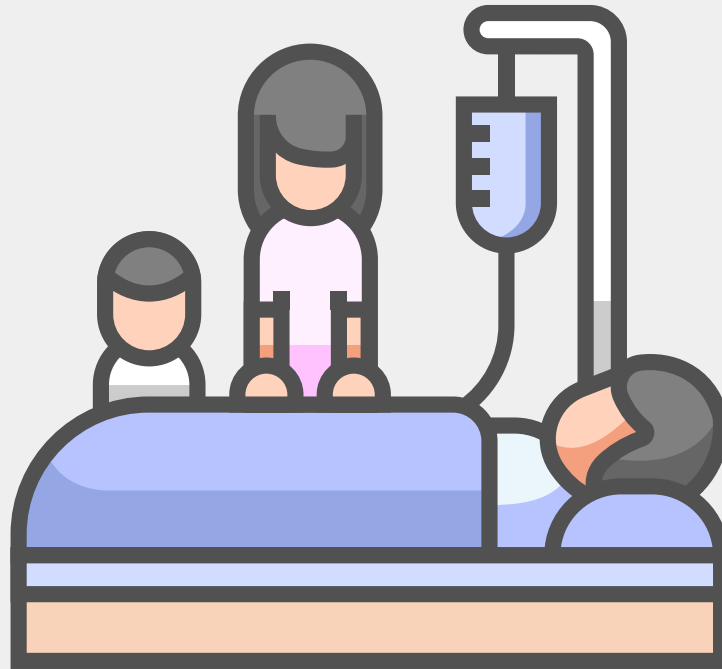
We say we are healthy when we feel like we can eat well, sleep, study, when we feel good and we want to do the things we like doing

We say we are unwell when we do not feel good, we are unable to eat, we are unable to sleep ...we do not feel like doing things we usually enjoy



STEP -2

BIG AND SMALL SICKNESSES





Well , sometimes when we don't feel well we take medicine... like when we have a cough, cold , bad stomach, headache , tooth acheetcetera.

These sickness are small sicknesses, we take medicines and they go away...

Explaining Big Sickesses ...



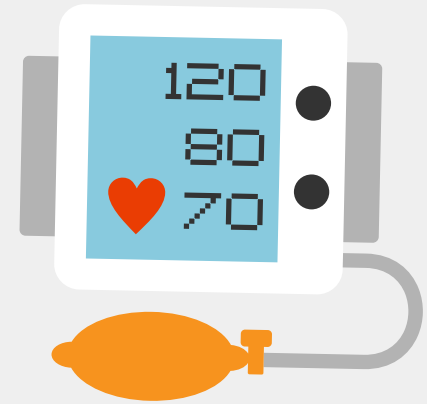
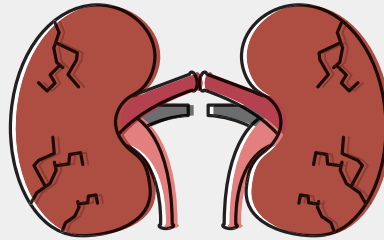
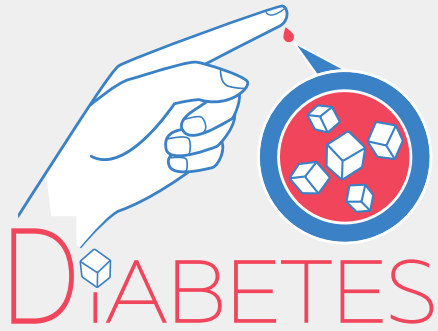
But sometimes, even with the medicines people have to go to the hospital because they need more or special help

to keep themselves healthy. These are usually the people with big sicknesses.

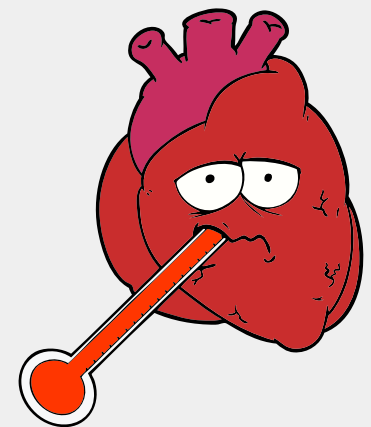
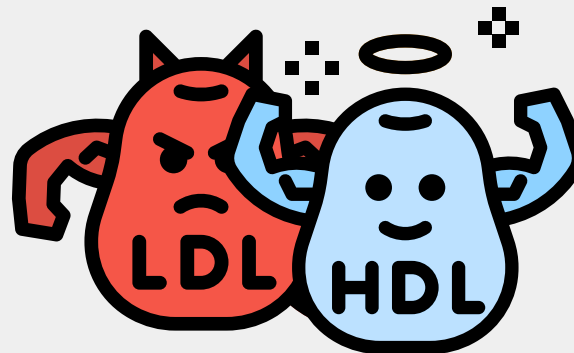
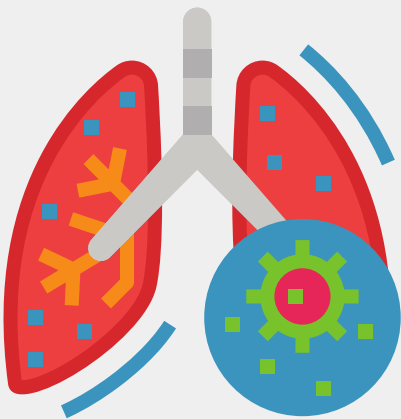
They may not go away so easily and may continue for a long time.

When we have big sicknesses we have to go to a doctor, and we take medicines for a long time maybe even for a lifetime,

If they stop the medicines they will become very sick...



Big Sicknesses are heart diseases, respiratory diseases, cholesterol, high blood pressure, diabetes, fatty liver, kidney stones ..



STEP -3

COVID AS A SICKNESS

*SO...YOU MUST HAVE
HEARD MANY
THINGS ABOUT THE
CORONA VIRUS ...*



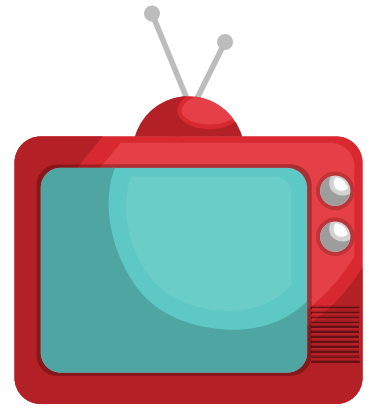
MAYBE ...



AT HOME



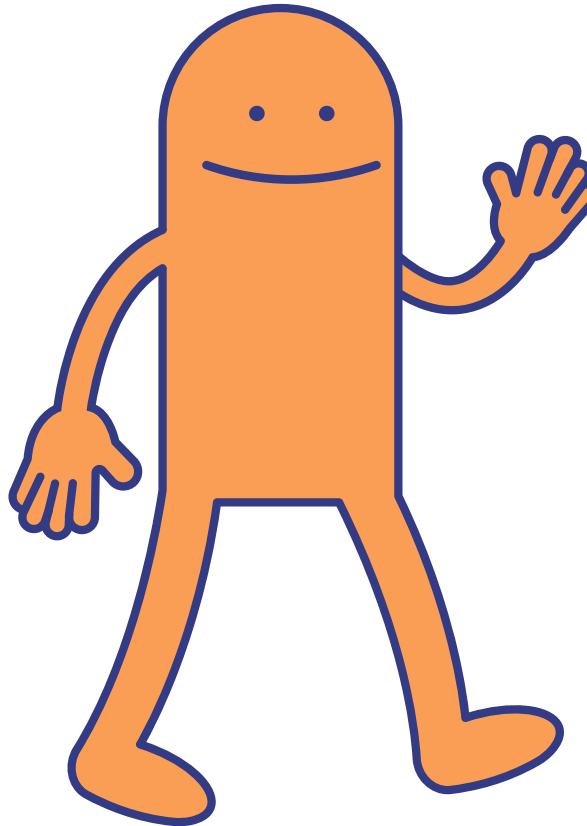
OVER A PHONE CALL



ON THE TELEVISION



IN THE NEWSPAPER



ONLINE

Well... you must be having
a lot of questions about it..

Where is this Virus...??

Who is this Virus?

Where has it come from ?

Why are people falling sick ?

When will it leave us alone ?

Will it ever go away?

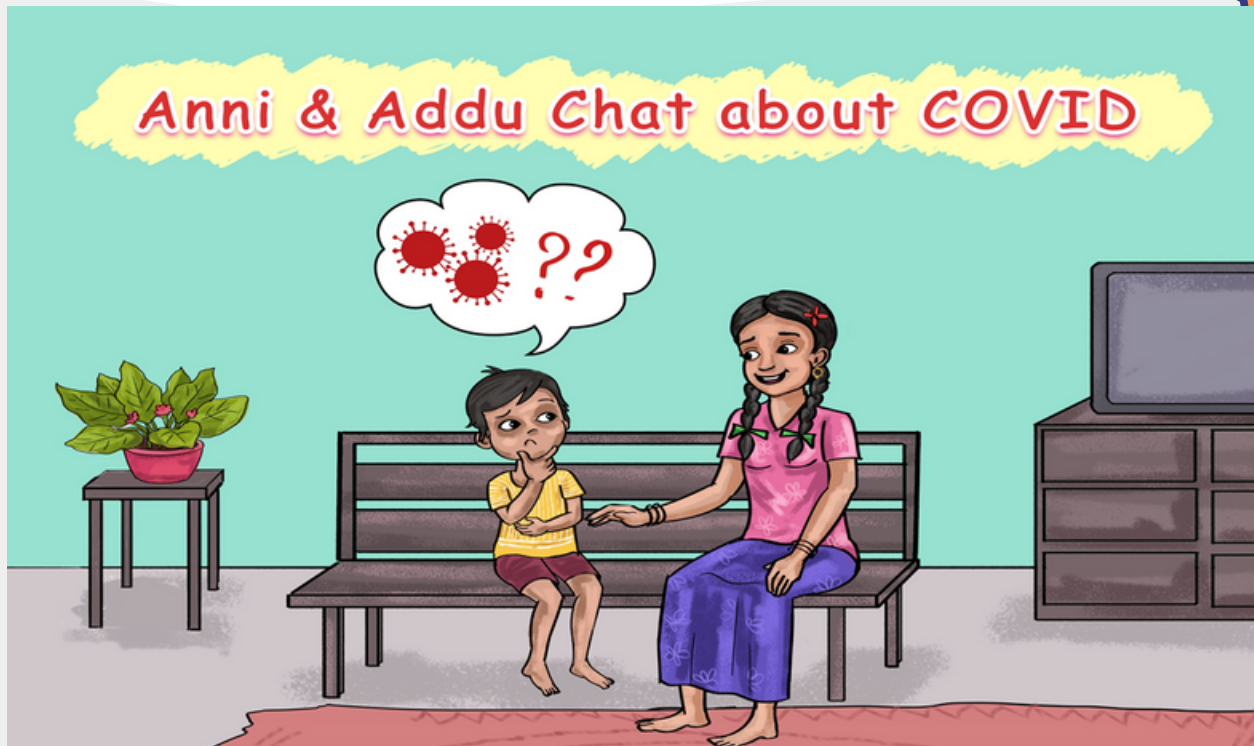
Will things ever be the same?



Well ...Corona is a newly discovered virus...
a virus is a very -very tiny creature...
invisible to the eye.
It makes people sick.
It causes a Disease called
COVID disease.



Anni & Addu Chat about COVID





Cold



Body Pain



Fever

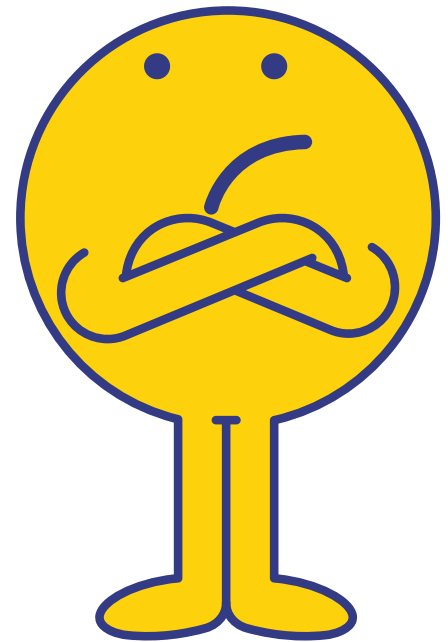
someone who gets COVID-19 or the Corona virus infection may get show symptoms like that of a common flu or sometimes they may not show any symptoms at all..

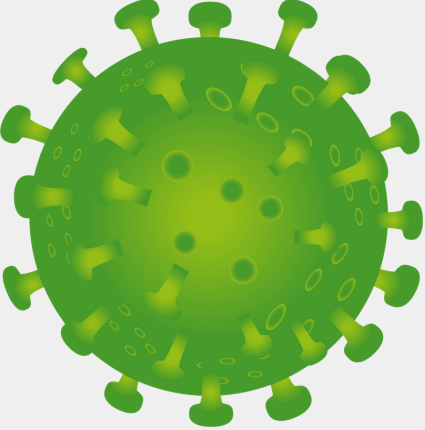


Shortness of
Breath



Cough





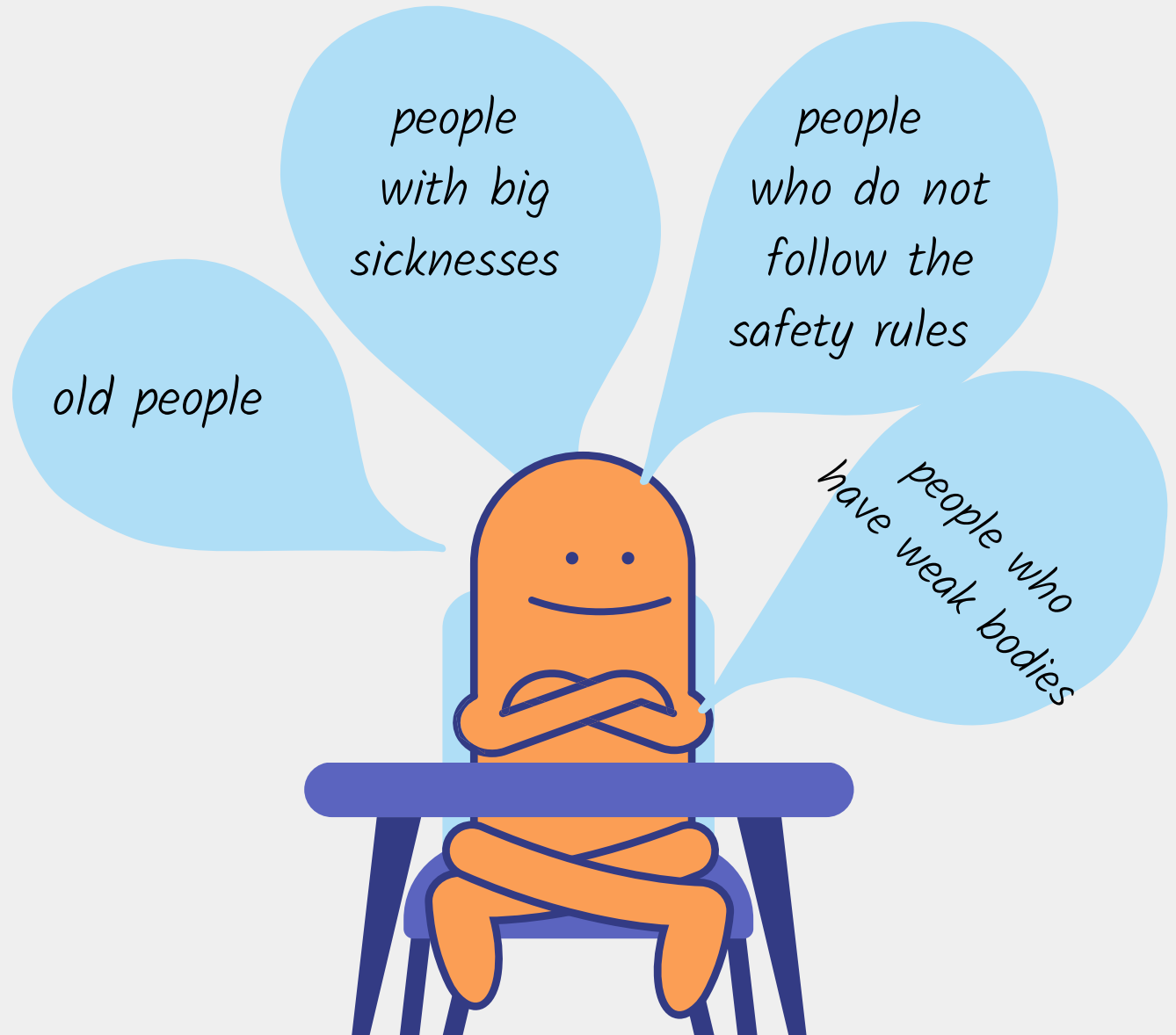
This virus can spread while coughing , sneezing , or through direct contact with a person who has Covid or by even being around a person who has Covid

There is no particular kind of person who gets sick with Covid Disease anyone can get it... boy..girl.. uncle ..aunt... grandma .. anyone and even children ..

*Run run run ...
.CO-RO-NA*



Although, all of us are at risk but some people are more likely to get Covid Disease like ...

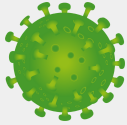


STEP -4

COVID SICKNESS - BIG OR SMALL

Covid can be a big sickness for some and for some it may only be a small sickness...

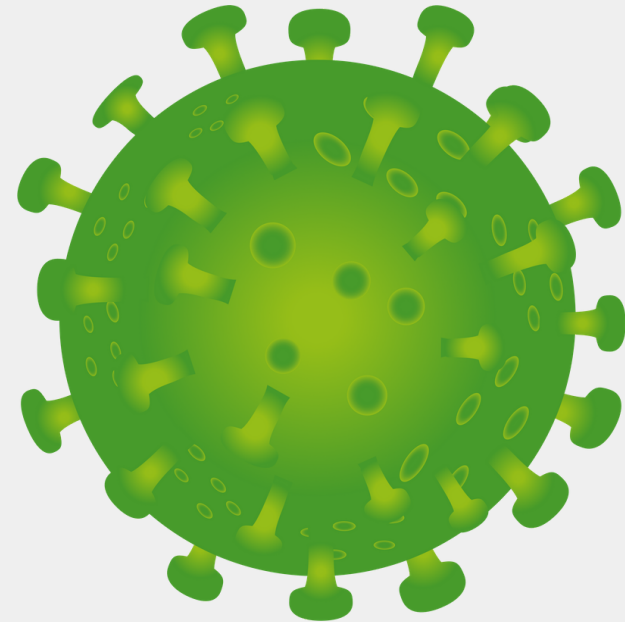




When COVID is a small sickness

Small sickness means it is not very strong.

People who have small sickness can rest, drink warm liquids.. stay at home, take medication and then they get better



When COVID is a big sickness

Some people may also have big sicknesses They may have to go to the hospital and stay there until they get better.

These are usually people who are old, or are weak...

If someone is in the hospital because they have to stay away from their family and all others we can still be in touch with them through voice calls ,video call or you can even write an email or a letter

Only in some cases, when the sickness is very very big then the medicines do not work and people don't get better.

When they do not get better even with the medicine, their bodies may stop working and they may die.



Well..it is quite natural for
you or anyone
to feel scared, anxious or worried.
Sometime when we see people get
sick we worry .

But you know
just like any other disease if we keep
ourselves protected by following some
safety rules
we can prevent Covid disease and
protect ourselves

STEP -5

REASSUARANCE AND HOPE



"We can also keep hoping that sick people get better..."



I can understand that things look sad and scary at the moment, but this is not permanent. Things will slowly get better...

The doctors have worked very hard - all day, all night to make a vaccine to keep us safe.

A vaccine is something that is put in our body to fight the Corona Virus, if it tries to attack our body.

So if we keep practicing the Safety Rules, take care of ourselves and get a vaccine, we can stay safe.

Remember, Vaccine does not guarantee 100 percent protection, so we cannot stop following the safety rules.

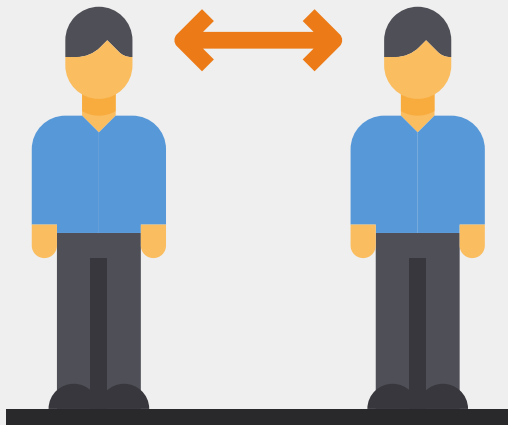


These safety Rules that we can follow to keep ourselves safe are



Wearing a Mask

1m



Maintaining Social Distance

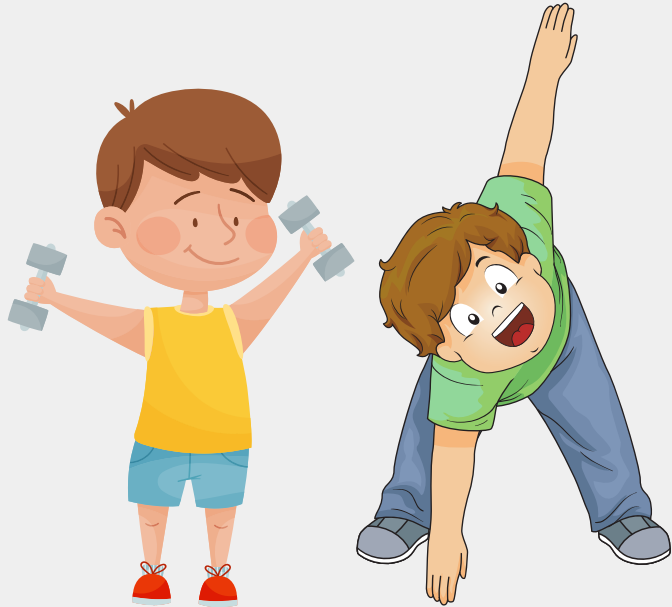


Washing and Sanitizing Hands



Staying at Home

To keep ourselves healthy we can also ..



Do some physical exercises



Eat Healthy



Read and Learn

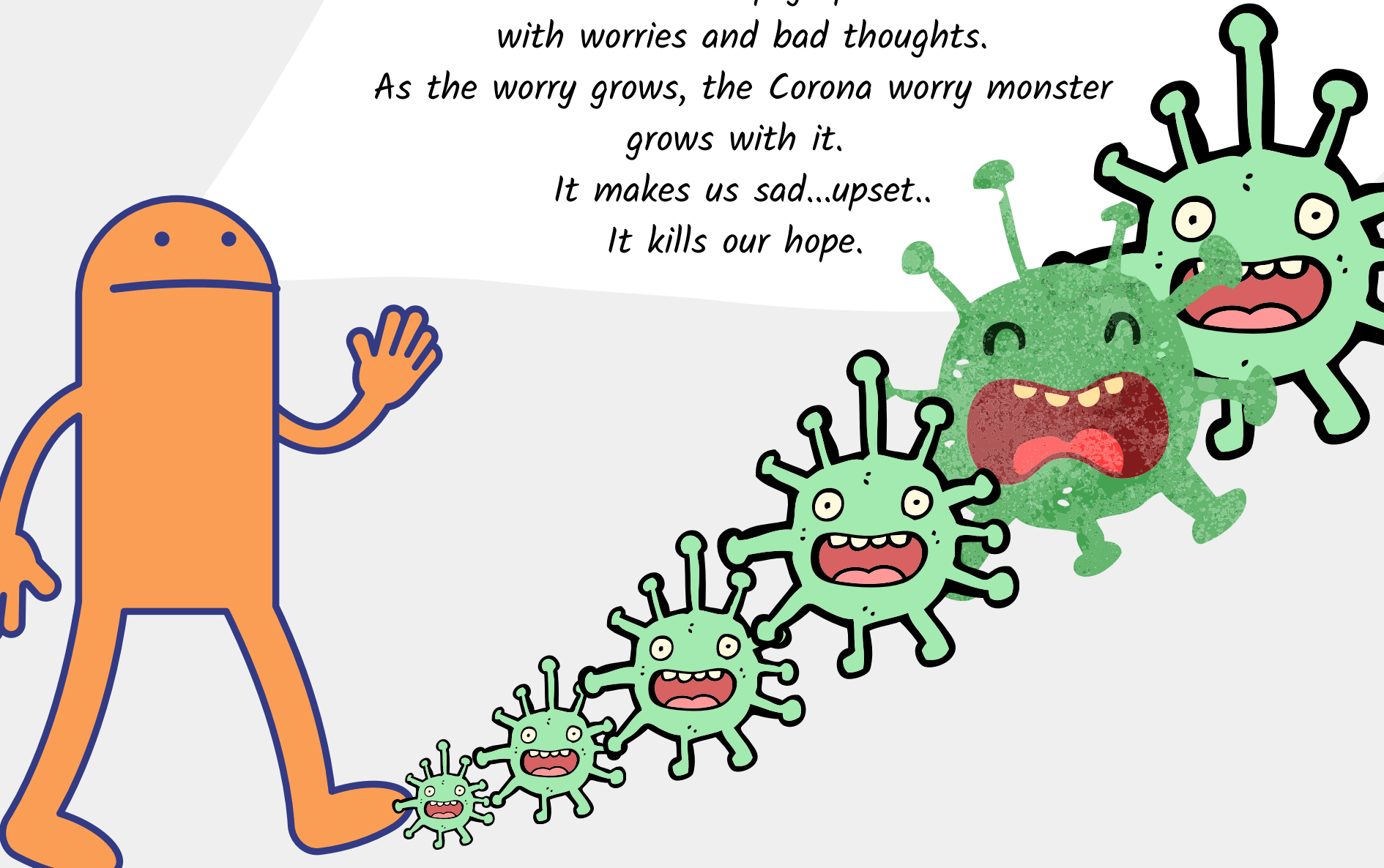


Sleep



Breathing exercises

We sometimes worry so much that
we even stop doing things we like.
And then all our empty space is filled
with worries and bad thoughts.
As the worry grows, the Corona worry monster
grows with it.
It makes us sad...upset..
It kills our hope.

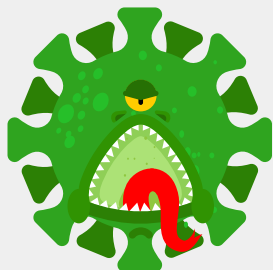


CORONA



**SAM.
SAMMM**

They are killing me ...HELLPPP!



*Oh Boy ! These kids are strong.
Plisss...dont kill me .*

**BAM.
BAMMM**



*so we must do activities that
make us happy and fill our minds with
happy thoughts and hope...*



STEP -6

ENCOURAGE CHILDREN TO ASK QUESTIONS

You can ask me any questions about the disease...don't be afraid to ask...

It is okay if you do not have any questions right now ...maybe you can come and ask me anything about COVID or the current circumstances later whenever you would like.

What to do in case parents are ill?

- **Restore normalcy by restoring the routine.**
- **Stay around check for any change in behavior.**
- **Communicate with the child. LISTEN and TALK**
- **Acknowledge the child's emotions of being sad, upset, angry, confused.**
- **If the child has anxiety, withdraws, has frequent crying spells, shows signs of self harm...consult a mental health professional**
- **Use deep breathing exercises, guided imagery in case the child has panic attacks or anxiety**
- **Reassure the child that he/ she is not alone**

REMEMBER ...

Children are curious.

They have questions.

They want to know.

They need to know.

They have the right to know.

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 Support, Advocacy & Mental Health Interventions for Children & Adolescents in Vulnerable and Disadvantaged Communities
 Department of Child and Adolescent Psychiatry, National Institute of Mental Health, Bangalore
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Saving Children from the Brink.
 ACTING UPON CHILD PROTECTION VULNERABILITIES IN THE COVID CRISIS.

Saturday, 15th May 2021
5:30-8:00PM



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 Support, Advocacy & Mental Health Interventions for Children & Adolescents in Vulnerable and Disadvantaged Communities
 Department of Child and Adolescent Psychiatry, National Institute of Mental Health, Bangalore
 Sponsored by: Ministry of Women & Child Development, Government of India

Worries...Fly Away!
 HELPING CHILDREN MANAGE COVID- RELATED ANXIETIES

Tuesday, 18th May 2021
5:30-8:00PM



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In My Heart Forever
 SUPPORTING CHILDREN THROUGH LOSS & GRIEF EXPERIENCES IN THE COVID CRISIS

Saturday, 22nd May 2021
5:30-8:00PM



SAMVAD's COVID Series...
"Children in the Covid Crisis...Like We Never Expected It to Be: The What and How of Working with Child Protection and Psychosocial Issues"