

Parkinson's in your life: a guide for teenagers

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Are you a teenager who has a family member with Parkinson's? This guide aims to answer your questions, and let you know who to ask if you want to know more.

When your parent, grandparent or another relative is diagnosed with Parkinson's, it can feel as though your life has changed forever. You may have a lot of questions about Parkinson's, but may not be sure where to find information or who to ask.

This booklet gives you the **facts** about Parkinson's, answers some of the **questions** you may have, and **offers information** about how to handle difficult **emotions**.

It also describes how Parkinson's may change things for you and your family, and **what support is available** if, for instance, you care for your parent, grandparent or family member, either by yourself or with others.

Although we have tried to cover lots of the things you might want to know, if you can, try to talk to your relative who has Parkinson's. Some people will find it difficult to talk about their condition, or may not want to worry you about it. But the best way to find out about Parkinson's is to speak to someone with the condition, **so don't be afraid to ask**.

You're not alone – there are many people who can give you information and support. You can email or phone Parkinson's UK if you have any questions. Turn to page 26 for details of how to get in touch. There is also a list of other useful organisations, helplines and websites on the same page.

Are you a parent or grandparent?

If you want more information to help you talk to your children or grandchildren about Parkinson's, this is just one of a range of resources we produce to help you with this. Call **0300 123 3689** or visit **parkinsons.org.uk/orderingresources** to order more resources.

This booklet was highly commended in the Information for Children category at the British Medical Association Patient Information Awards 2015.



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Three facts about Parkinson's

Parkinson's is a complicated condition, but before we go on to talk about it in depth, there are three things you should know.

Parkinson's affects the brain and movement

Parkinson's is a medical condition caused when nerve cells in the brain have died. These nerve cells make a chemical called dopamine, and a lack of dopamine affects normal movement. People with Parkinson's move more slowly and stiffly. They may also have a tremor or shake, usually in one arm or hand. Their condition can change from day to day, or even hour to hour.

Sometimes, their muscles stop working altogether and they 'freeze' in one position – sometimes just for a few seconds, or at other times, for several minutes.

The shortage of dopamine causes other problems, too. These can include daytime sleepiness, anxiety, depression, poor memory, problems going to the toilet and falls.

Parkinson's affects everyone differently

Parkinson's affects around one person in every 500. Most are aged 50 or over, but people who are younger than 50 can get it too.

As the amount of dopamine in the brain is gradually lost over many years, Parkinson's will get worse. But the symptoms someone has and how quickly their Parkinson's develops will be different from one person to the next.

Parkinson's can be treated

While there is no cure for Parkinson's at the moment, there are drugs that can help control the main symptoms, such as tremor, or problems with balance and co-ordination. Other treatments that can help include physiotherapy (physical treatments that help people improve their movement), occupational therapy (where therapists help people find ways to carry out everyday tasks and activities), and speech and language therapy. Sometimes surgery can help.

When someone is diagnosed with Parkinson's

Finding out you have Parkinson's (getting diagnosed)

The symptoms or signs of Parkinson's develop slowly. They can have a lot in common with other medical conditions, so it can take a long time until a specialist doctor can definitely tell someone they have Parkinson's. This means your parent, grandparent or family member may have been worrying for a long time before they discovered what is wrong.

Your parent, grandparent or relative will be told they have Parkinson's by a doctor who specialises in Parkinson's. He or she might start them on a drug treatment straight away to help with the symptoms.

Some people may be shocked by finding out they have Parkinson's. Others may feel relieved to find out what's causing their problems. Another reaction can be disbelief. Your parent, grandparent or relative may try to ignore the fact that they have Parkinson's, especially if their symptoms are mild. Turn to page 15 for more about emotions within the family.

When I found out my dad had Parkinson's it was crazy... a really hard time. But when we all sat down and talked about it I felt much better.

Ryan, 13

mann

Questions you might have

Q: Why my family?

A:Wedon'tknowexactlywhypeoplegetParkinson'sandtheredoesn'tappear tobeanysinglecause.Weknowit'snotinfectious(soyoucan'tcatchit,likea cold) and it's no one's fault that they get it.

Q: Will I get it?

A: It's highly unlikely. The cases where it's been found in more than one family member are very rare.

Q: Does Parkinson's cause death?

A: Generally speaking, how long people live is not greatly affected by Parkinson's. The drugs used to treat it are very good at controlling movementproblems, and many people carry on working and doing the samethings they did before they had it. However, if some one's symptoms get worse over a period of time, it can make the person less able to get around and more likely to pick up infections.

Q: Is it the same as dementia?

A:No.Dementiadescribesacollectionofsymptomsincludingmemoryloss, andproblemswithunderstanding,communicatingandcompletingeveryday tasks. Although Parkinson's is also a condition that affects the brain, it isnotthesameasdementia.MostpeoplewithParkinson'scontinuewith activities and have a healthy social life.

Also, having Parkinson's doesn't mean someone will get dementia. As people with Parkinson's get older, the chances of them developing dementia do get higher, but not everyone gets it.

How you might feel

When your parent, grandparent or relative has Parkinson's, you may experience different emotions, such as sadness, guilt, fear, anger or frustration. Some people say they feel numb and have no feelings at all, or that they don't want to talk or think about the situation.



- Remember that, for many people with Parkinson's, the condition will progress very slowly. It may be a long time before your relative's symptoms make a big difference to their everyday life.
- Parkinson's UK supports research into Parkinson's and scientists are constantly looking at ways to improve treatments and, ultimately, to find a cure for the condition.
- You are not alone. There are other young people out there who have parents or relatives with Parkinson's or similar conditions. You can find support from other young people in the same situation as you. Turn to page 28 for more information.

- There are also other organisations and professionals you can talk to. See page 26 for contact details.
- You might find it helpful to keep a journal and write down your thoughts.
- Try not to worry or feel guilty. It's important to keep a balance in your life. This means not constantly thinking about Parkinson's, or trying to forget it exists. You can still care about your loved ones, and enjoy going out and seeing your friends.

Talking can make you feel better. Ask the person with Parkinson's, or another member of your family, if you have any questions. If they do not want to talk about it, there are other people who can help (see page 27).

Write down any questions you have here:

~

My dad was diagnosed with Parkinson's about two years ago, when I was 16 years old – or at least that's when I found out. I think my parents knew beforehand but did not want to tell me or my older sister until after our important exams.

At the time, I did not know how to deal with this huge change as his symptoms got worse quite suddenly from barely visible to very restricting. I have realised now, after having come to terms with my dad's condition and learning more about what he wants and needs as well as the condition in general, that during the first few months I did not cope well with it at all. I didn't know who to turn to and as a young person the condition was completely new to me. I didn't want to interrupt my parents as I felt guilty that I was so upset when I wasn't the sufferer or the main carer. My sister wasn't living at home and none of my friends knew anything about the condition. I also felt embarrassed by it as it is seen as a fairly mysterious condition.

Recently, after having used the helpful information about the condition on your website, I feel a lot more comfortable with it although I know it will never be easy.

sam

Elinor, 18

Symptoms of Parkinson's

There is a long list of Parkinson's symptoms, but not everyone with Parkinson's has them all or the same combination. People's symptoms may also change often. Sometimes this can happen very quickly. Everyone's experience of Parkinson's is different – that's partly why it is difficult to diagnose.

Main movement symptoms

Parkinson's mainly affects movement. The main problems are:

Slowness – people with Parkinson's have trouble starting movements and it takes longer for them to do things. Sometimes their movements get stuck. This is called 'freezing'. They can also lose their balance easily and lack co-ordination.

Stiffness – Parkinson's can stop the muscles from stretching and relaxing. This makes the muscles painful and they may cramp.

Tremor – this is one of the most noticeable signs of Parkinson's, but as mentioned earlier, not everyone will get this symptom. It can make everyday tasks difficult, from using a computer mouse to eating and drinking. It usually gets worse when someone is stressed or excited.

Problems with movement can mean people with Parkinson's:

- have difficulty with tasks that need small hand movements, such as writing, doing up buttons and shaving
- have a weak grip, making it difficult to hold cutlery, pens and so on
- are unable to walk long distances
- can lose balance, trip and fall
- can find it hard to carry out day-to-day movements, such as rolling over in bed, or getting in and out of the bath

Other symptoms

As well as difficulties with movement, people with Parkinson's might have other symptoms, such as:



These are called non-motor symptoms and they can have a big effect on your parent's, grandparent's or family member's life.

Parkinson's symptoms may become more noticeable if the person with the condition is unwell or becomes stressed, worried or nervous.

It is important that the person with Parkinson's eats healthily and keeps up with their social activities. Research shows that those with a positive attitude enjoy better quality of life than those who 'give up'.



Treatments and therapies for Parkinson's

Drug treatment

The main way of treating Parkinson's is with drugs. There are several types of drugs available and they act in different ways to manage some of the symptoms. People with Parkinson's usually have to take drugs regularly, often at the same time every day.

Although Parkinson's drugs work really well at controlling the symptoms of Parkinson's, they also have side effects. These usually happen after someone has been taking the drugs for a long time.

Drug regimens are often very complicated, and may need changing as the Parkinson's progresses, or to reduce any side effects.

Find out more: see our website, parkinsons.org.uk/drugtreatments

Surgery

There is a type of surgery called deep brain stimulation that can help control some Parkinson's symptoms. As with all surgery, there are risks involved, and it's not suitable for everyone with Parkinson's. It's mainly used to treat people whose Parkinson's can't be managed well by drug therapy and who do not have dementia.

Therapies

As well as drugs, there are therapies aimed at keeping the person with Parkinson's active and independent. For instance, physiotherapy uses exercises to strengthen muscles and improve flexibility. Speech and language therapy can help people talk more clearly and help make swallowing easier. Occupational therapy looks at the everyday tasks that a person with Parkinson's finds difficult, and comes up with ways to make them easier.

Who's who?

Your parent, grandparent or relative may see different health professionals at different times, either at their home or at a clinic, hospital or other setting. The professionals can include a doctor or GP, a Parkinson's nurse (if there's one in your area), an occupational therapist, physiotherapist and speech and language therapist. They may also see a Parkinson's specialist one or more times a year.

Living with someone who has Parkinson's

Changes in the family

You may see little or no change in your parent, grandparent or family member after they find out they have Parkinson's. But they may have to rest often and they will do things more slowly than they used to – from walking to talking. This can be frustrating for them and they may express that. At some point they may become upset, short-tempered and tired.

Doing things differently

Other things may change: for instance, your parent, grandparent or relative might have to give up work or an activity they have always enjoyed, or change it for something else. Sometimes, life in a family affected by Parkinson's can be frustrating, for instance, trips might be cancelled suddenly or your parent might not be able to drive you somewhere.

On the plus side, Parkinson's can help bring families closer together. You may find that you talk and help each other more.

Positivity

Many people with Parkinson's adopt a positive way of thinking – they want to get the most out of life and not let Parkinson's beat them. They take up new challenges, do more sports and activities, and become involved with local group and fundraising.



Your emotions

When someone you love has a medical condition such as Parkinson's, you may feel more difficult or extreme emotions, including sadness and anger. There is no right or wrong way to feel. Everyone is different. If things are getting you down it's important to talk about it and find ways to help you feel better. Having a creative outlet, such as writing poems and drawing, is a good way to express your emotions. Physical exercise can make you feel good, too, as it makes the body release chemicals that cheer us up, plus it's a good way of keeping in touch with friends.

Tips on managing emotions

Fear

You may feel scared about what the future will bring for you and your family. If your parent, grandparent or family member is moody or down, you can be afraid of upsetting them. Talking about your fears and taking time out to have fun and forget about your worries can help. Don't be afraid to ask the person with Parkinson's about the condition or how they feel – they may be pleased for the chance to talk about it.

anger

This can build up inside and come out in ways that can make you feel even worse, such as having arguments. Find a safe way to express anger – punch a pillow, run around the park or play a computer game.

Physical activities are especially good outlets for anger, because they get rid of the tension you are holding in your muscles. You can also write down all the things that make you angry, screw up the paper and throw it away. Once you release angry thoughts from your head, they become less powerful.



WORRY

Write down your worries or talk to people you trust, such as a teacher or family member. You can share your worries online – see page 27 for information on safe sites – or call one of our helpline advisors (see page 26 for details).

Guilt

You may feel as though you shouldn't enjoy the normal things of life when your parent, grandparent or relative has Parkinson's. Remind yourself that they want you to be happy and that feeling bad won't help you or them. Treat yourself to some good times, as they will benefit everyone. If you find you can't enjoy things that you used to, it's important to talk to someone you trust about this.

Jeal ousy and resentment

It's natural to think, 'Why me? Why my family?', and feel jealous of others who are not affected by Parkinson's. It can be especially hard if you have more to do at home if your parent, grandparent or family member is tired or unwell. Try to not to focus on negative feelings. Instead, think about things in your life that you're happy with and remember that everyone faces problems at some point in their lives.

Lonel iness

You may think that no one understands what you're going through. But there are many young people whose parent, grandparent or relative has Parkinson's or another medical condition. It can help to join local groups or online forums. Turn to page 27 for details of how to find groups in your area, or places you can chat to others in a similar situation to you.

You may also feel lonely or left out if your parent, grandparent or relative won't talk to you about Parkinson's. It may be that they are just trying to protect you by not telling you everything. If this is the case, try to talk to another family member. Sharing how you're feeling with the family can be a good way to support each other.



sadness

You may cry sometimes, want to be by yourself or feel run down. All this is normal. But remember you need to look after yourself properly, and it's important that you have fun and laugh when you get the chance. Laughter is important for everyone, and it's healthy too! Try to keep doing the things you like and make you feel good, from going out with friends to playing football. If the sadness does not go away, tell someone you trust.

11

If your mum, dad or family member has Parkinson's, don't just see it as a disease. Look for the positives – it's all about having a positive attitude.

Thomas, 17

Embarrassment

If your parent, grandparent or family member has a tremor or difficulty moving, it can make people stare and ask questions. Don't feel bad if you are embarrassed. Remember that not everyone understands or has even heard of Parkinson's. You don't have to explain anything you don't want to. If you want to help raise awareness of Parkinson's, you can give people our free leaflet *A quick introduction to Parkinson's*. See the back cover for details of how to order this.

Use this space to write down how you feel:

Who can I talk to?

Learning about Parkinson's and what help is available can reduce your worries and fears. If you have questions, then ask your parent or another trusted adult. You could ask to go with your family member with Parkinson's when they see their doctor or specialist. Make a list of the questions you would like to ask these professionals, so that you don't forget (there's space on page 9 to do this).

There are also several organisations that offer listening services for young people – see page 27 for details.

Counselling

You may find it helpful to speak to a counsellor. A counsellor is someone who is specially trained to listen to people's problems without making any judgements about them. Many young people say that if they are listened to, and their worries taken seriously, they feel much more positive, confident and in control of their life.

If you want to speak to a counsellor, then your GP, Parkinson's nurse (if there's one in your area), or a social worker can help find one for you. Or, your school may have a counsellor who comes in to listen to students' problems. Or turn to page 27 for organisations that offer help online, or who can put you in touch with a counsellor in your area.

School and friendships

Parkinson's can seem like such a big problem you may find day-to-day activities hard to get on with. If you're struggling to get up for school, can't concentrate in class or finish homework, then you need to tell your school. They can help get you the support you need.

You might feel awkward telling your friends that a loved one has Parkinson's, or be worried that they won't understand. Maybe you can't or don't want to go out as much as before. Sharing your problems with friends can help you feel better. It may be that not everyone will understand what you're going through, but some will.

If you want to help people at your school understand more about Parkinson's, you could ask a teacher to bring up the subject in a Personal, Social, Health and Economic (PSHE) class. Or you could contact Parkinson's UK to ask if a member of the local support team can visit your school to do a talk on Parkinson's. See page 26 for details of how to get in touch.



Another option is to contact local young carers' organisations, so you can chat to other young people who have a family member with a long term illness or disability. Parkinson's UK or your local information and support worker will have details – see page 26.

School has been really good. They offered me a space to go and talk to someone. I always knew I could talk to them if I couldn't talk to my family.

Ryan, 13

Being a carer

If you're under 18 and help to support a parent, grandparent or relative with Parkinson's, either on your own or with other family members, you're a 'young carer'. Although you might not help your parent or relative directly, you may still need extra support, such as:

- someone to talk to. This could be another young person or someone you trust, such as a doctor, teacher or a family friend
- information, including where to go for advice and support

You may not feel like you want to talk about what you're going through, but it's important to find someone to share your worries with. Although caring can be a really good thing to do – you're helping someone you love and learning skills that will be useful later in life – it may have an effect on your school work and social life.



Getting support

No one – whether they are a young person or an adult – has to be a carer if they don't want to be. Accepting help gives you a better chance of looking after your own health and wellbeing.

You, or your parent or guardian, should tell your GP that you are a young carer. They can help you access any support you may need.

You, or your parent or guardian, should also ask for a carer's assessment. This is organised by your local authority. An assessment will look at the needs of the person you care for, and how much your caring role affects your everyday life. It can result in extra help being given to your parent, grandparent or relative and more free time and support for you. An assessment is available to you whatever your age. You can speak directly to your local authority for advice, or ask someone in your family or at school or college to help you do this.





Help with education

Ask your school or college whether they can arrange flexible courses or tuition if this would be helpful. Your GP may be able to help you with this, or let you know about others who can help.

Young carers' groups

Around the UK, there are many young carers' projects and groups that can give you support and help from other young carers. Some have websites where you can get in touch with each other. See page 28 for details.





Suhag, 11, is the main carer for her dad Kolomdor, who was diagnosed with Parkinson's in 2009. Suhag's local Parkinson's UK information and support worker is helping her family to get the support they need.

I don't really remember when my dad first told me he had Parkinson's. I don't know much about what it is, but I do know he will always have it.

His hands shake, and he can't carry things. He also forgets stuff. We live on the seventh floor of a tower block, and sometimes the lift is broken. I do the shopping and help my dad carry things up the stairs as he can't do it by himself.

I also do the cooking and washing up – my dad's favourite is chicken curry. I don't know the recipe so he tells me how to make it!

Sometimes I tidy up, and help my dad take his medicine. I don't mind helping, but I do get tired.

When I help all the time it's too much, especially when I've got homework. If we lived nearer our relatives they would be able to help out. But it's too far for them to come very often.

More information and support

Learn more about Parkinson's

Visit our website **parkinsons.org.uk/publications** to download or order free information leaflets. Useful ones include *Parkinson's and you*, and *A quick introduction to Parkinson's*.

Our helpline

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**

Our helpline can also put you in touch with one of our local information and support workers, or a Parkinson's nurse (if there's one in your area). They can also tell you about local groups and services.

For health information

NHS 111 (England)

This service offers health advice and reassurance, 24 hours a day. 111 www.nhsdirect.nhs.uk

NHS24 (Scotland)

Health care advice and information, 24 hours a day, for people in Scotland. 08454 24 24 24 www.nhs24.com

NHS Direct Wales

0845 4647 www.nhsdirectwales.nhs.uk

NI Direct (Northern Ireland)

www.nidirect.gov.uk

Support and Listening services

Childline

Free and confidential 24-hour helpline for children and young people, plus online counselling service.

0800 11 11 www.childline.org.uk

Get connected

Free, national and confidential helpline for young people under 25 where you can discuss your problems or worries. Webchat, text and email also available, plus online directory to find local services. **0808 808 4994** 1–11pm every day Text **80849** www.getconnected.org.uk help@getconnected.org.uk

Samaritans

This organisations offers a confidential 24-hour helpline where you can talk about your feelings or what's going on in your life. Or you can speak to a volunteer in person at one of 200 branches in the UK or Ireland.

08457 909 090 www.samaritans.org jo@samaritans.org

The Site

Support and information resource for 16–25-year-olds, with discussion boards, live chat and an 'ask an expert' service. Also works as a local advice finder.

www.thesite.org

Youth Access

Find out about information, advice, counselling and support services for young people in your area. www.youthaccess.org.uk

Royal College of Psychiatrists

Offers free leaflets on coping with stress and anxiety: When bad things happen and U can cope! 020 7235 2351 www.rcpsych.ac.uk

Breathing Space (Scotland)

Offers a listening ear for young men in Scotland who are feeling sad, lonely or struggling to cope.

0800 838 587 Monday to Thursday 6pm–2am, Friday to Monday 6pm–6am. www.breathingspacescotland.co.uk

Information for young carers

Barnardo's

A children's charity that runs young carers projects across the UK. As well as advice and support there are social events and the chance to meet other carers.

020 8550 8822 www.barnardos.org.uk

Carers Direct

NHS website that offers a free confidential helpline, SMS (text) service, online adviser, and email advice. There is information on young carers' rights, and advice on looking after a parent.

0808 802 0202 Monday to Friday 9am–8pm, weekends 11am–4pm (translation service available) www.nhs.uk/carers

Carers Trust

This charity runs YCNet, a website and online support for carers aged 18 or younger. There are discussion boards and chat rooms, and you can post questions to youth workers and 'agony aunts'. It also organises Young Carers Projects, delivering 'fun, friends and advice'. Visit the website to find out if there is a project in your area.

0844 800 4361 www.youngcarers.net help@carers.org

Scotland office

0141 221 5066

Wales office 0292 009 0087



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If you have comments or suggestions about this booklet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible.

Editorial and Creative Services, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ.

Or you can email us at publications@parkinsons.org.uk. Thanks!

Please tick...

- I have Parkinson's. When were you diagnosed?
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this booklet from?

Please tick...

- GP, specialist or Parkinson's nurse
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- 🗌 Other

How useful have you found this b	ookle	t?			
(1 is not useful, 4 is very useful)	1	2	3	4	

Have v	vou found	the publicat	ion easv to	read/use?	Yes	No
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Continued over the page

Were you looking for	any information that wasn't covered?
Do you have any othe	er comments?
in joining our informa and we'll be in touch.	
Membership	Information review group
Address	
•	
	background?
What is your ethnic b Please tick Asian or Asian Briti	

Thank you to everyone who contributed to and reviewed this booklet:

Dr Lisa Honeyman, Clinical Psychologist

Jane Mills, Nurse Consultant

Thanks also to the teenagers, whose family members or friends have Parkinson's, who provided feedback.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

Our information

All of our most up-to-date information is available at **parkinsons.org.uk/informationsupport** If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/orderingresources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**



Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK 215 Vauxhall Bridge Road London SW1V 1EJ

Free confidential helpline **0808 800 0303** (Monday to Friday 9am–7pm, Saturday 10am–2pm). Interpreting available. NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk parkinsons.org.uk

Order code: PKB085

Last updated December 2013. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

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