

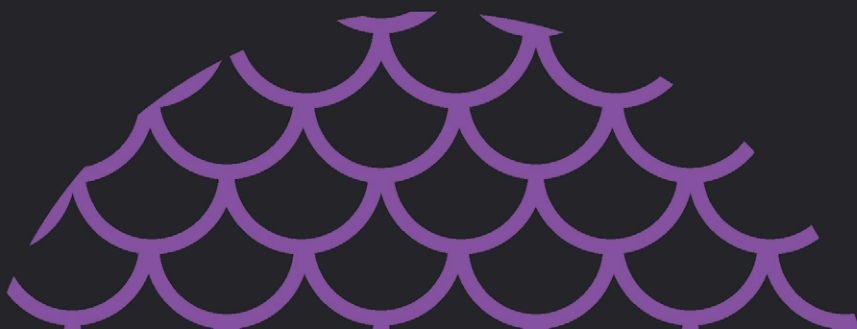


EMERALD POINTS

# AUTISM AND COVID-19

Strategies for Supporters to Help  
Autistics and their Families

**MATTHEW BENNETT**  
**EMMA GOODALL**



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## Strategies for Supporters to Help Autistics and Their Families

BY

**MATTHEW BENNETT**

*Independent Researcher, Australia*

And

**EMMA GOODALL**

*University of Southern Queensland, Australia*



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*First and foremost, we would like to dedicate this study to all autistics who have either lost their lives or who have experienced serious illness due to COVID-19. We would also like to dedicate this book to the parents of autistic children who have been negatively impacted by the COVID-19 pandemic. Finally, we would like to acknowledge and dedicate this research to those healthcare professionals who are providing medical care and support to autistics and their families during the COVID-19 pandemic.*

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# ABSTRACT

**Background:** The first documented case of coronavirus disease (COVID-19), a disease caused by the virus severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), occurred about 1 December 2019 in Wuhan, China. By late December 2019, a cluster of atypical pneumonia cases emerged in this city. Most of the patients in this cluster had a connection to the Huanan Seafood Market, which suggests that SARS-CoV-2 was zoonotic in origin. On 30 January 2020, the World Health Organization (WHO) declared COVID-19 a ‘public health emergency of international concern’. On 11 March 2020, the WHO re-classified the COVID-19 outbreak a global pandemic. This pandemic has undoubtedly had a transformative impact on our society, economy and daily lives. It has also had an impact on autistics and their families.

**Objectives:** This study has two objectives. First, to present a synthesis of the literature about the impacts of the COVID-19 pandemic from the perspective of autistics and their families and to highlight any gaps in this field of research. Second, to conduct an online survey that will collect the views of autistics or parents raising autistic children about the gaps identified from the synthesis. To achieve these two objectives the following three research questions were posed:

- (1) What are the experiences of the COVID-19 pandemic from the perspective of parents raising autistic children?
- (2) What impacts has the COVID-19 pandemic had on autistics?
- (3) What are the gaps in our understanding about the impact of the COVID-19 pandemic on autistics and their families?

**Source and Methods:** With the intention of discovering studies that could answer the three research questions, a search of PubMed, using the key terms *autis\** AND *COVID\**, was conducted on 4 July 2021. This search

resulted in the identification of 188 citations. All of these citations were subjected to a *Preferred Reporting Items for Systematic Reviews and Meta-analysis* analysis process. Using this process, 21 studies were identified that were deemed to answer one of the three research questions. From this literature three gaps were discovered, specifically vaccine hesitancy among autistics and parents raising autistic children, the experiences of autistics living with COVID-19 disease and parenting an autistic child during the COVID-19 pandemic. To address these gaps an online survey was developed and distributed on two separate occasions to autistics and their families. During its first distribution it was open for five weeks, from 13 July 2021 to 20 August 2021, and was completed by 32 respondents. During its second distribution it was open for six weeks, from 6 March 2022 to 17 April 2022, and was completed by 34 respondents.

**Findings:** An examination of the retrieved literature and the results from the two online surveys revealed that autistics and their parents have experienced a considerable amount of stress during state-imposed lockdowns and social distancing requirements. The results collected also showed that autistics were generally receptive to receiving a vaccine that can prevent them from developing COVID-19. A follow-up search of the literature indexed on PubMed using the same search permutations as the previous search was conducted on 27 May 2022. This follow-up search confirmed the results collected from the two online surveys.

**Conclusions:** To our knowledge, this is one of the first books about the impacts of the COVID-19 pandemic on autistics and their families. It is also the first study about vaccine hesitancy among autistics and their families, the experiences of autistics living with COVID-19 disease and parenting an autistic child during the COVID-19 pandemic. However, despite these contributions to this emerging and rapidly evolving public health crisis, the results reported in this study should be cautiously adopted since they were based on a small number of participants who all had the ability to access and read an online survey that was published in English.

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# LIST OF ACRONYMS

AAoM	Autism Alliance of Michigan
ABC	Aberrant Behavior Checklist
ASD	Autism spectrum disorder
COVID-19	Coronavirus disease
GAD-7	Generalised Anxiety Disorder Scale
GPS	Global positioning system
MERS-CoV	Middle East respiratory syndrome
NHS	National Health Service
PHQ-9	Patient Health Questionnaire-9
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analysis
RNA	Ribonucleic acid
SARS-CoV	Severe acute respiratory syndrome coronavirus
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
TD	Typically developing
USA	United States of America
WHO	World Health Organization

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## ABOUT THE AUTHORS

**Dr Matthew Bennett** holds a PhD in Disability Studies from Flinders University, Australia. He has lectured in Disability Studies at Griffith University, Queensland. He has also advised the Australian Government's Autism CRC and has published articles for the *Journal of Autism and Developmental Disorders*. He is actively involved in supporting autistics to achieve their potential in society by disseminating his knowledge about the autism spectrum via lectures, conference presentations and publications.

**Dr Emma Goodall** is an adjunct research fellow at the University of Southern Queensland, holds a PhD in Education, focused on teaching students on the autism spectrum. She is an executive member of the Australian Society for Autism Research, independent researcher through Healthy Possibilities, a published author and keynote speaker in the areas of autism, sexuality and relationships, education and interoception.

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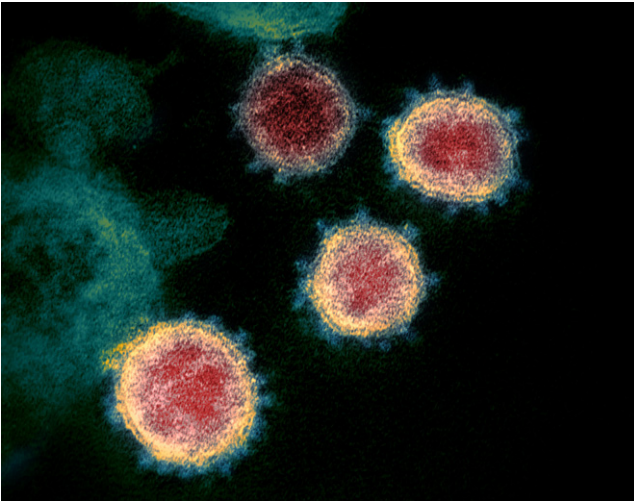
# INTRODUCTION

## 1.1 INTRODUCTION

Coronaviruses are a family of enveloped positive-sense single-stranded ribonucleic acid (RNA) viruses that were first discovered during the 1960s. Compared to other RNA viruses, such as the Human Immunodeficiency Virus Type 1 that is between 9,200 to 9,600 nucleotides, coronaviruses have larger genome sizes, ranging from 27 to 34 kilobases ([German Advisory Committee Blood, 2016](#)). The name coronavirus is derived from the Latin word ‘corona’, which means ‘crown’ or ‘halo’. It has been given this name due to its outer appearance ([Valencia, 2020](#)) (see [Image 1.1](#)).

There are several different types of coronaviruses that are known to cause disease in humans, including Alphacoronaviruses and Betacoronaviruses. It is widely accepted, particularly among those who study coronaviruses, that Alphacoronaviruses and Betacoronaviruses originated from the bat species *Rousettus leschenaultii*. Not all types of coronaviruses, however, can cause serious illness or death. For example, strains 229E and NL63 of Alphacoronaviruses and strains OC43 and NKU1 of Betacoronaviruses often cause mild flu-like symptoms in humans. However, the Middle East respiratory syndrome (MERS-CoV), severe acute respiratory syndrome coronavirus (SARS-CoV) and severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) commonly cause severe respiratory illnesses in humans ([Valencia, 2020](#)).

The cross-species transmission pathways that coronaviruses have traversed to infect humans from animals has been researched. During 2012, for example, MERS-CoV transmitted from a bat to a camel and then to humans while during 2003 SARS-CoV went from a bat to a civet cat and then to humans ([Kirtipal et al., 2020](#)). Currently, the transmission pathway that



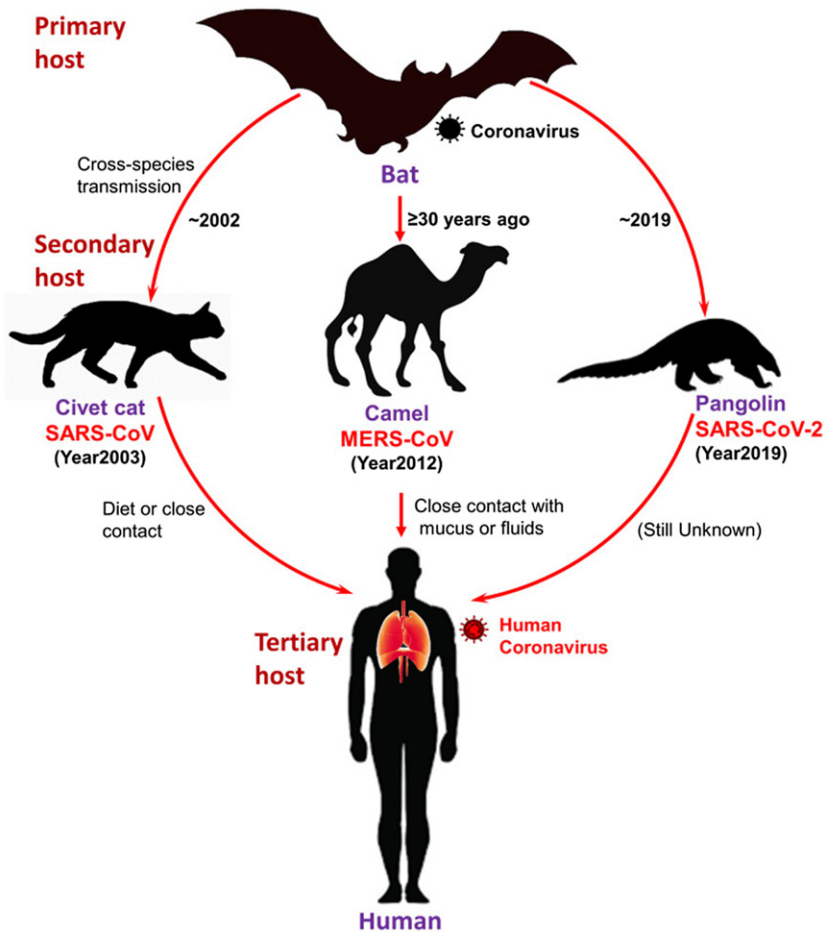
Source: [National Institutes of Allergy and Infectious Diseases \(2021\)](#).

**Image 1.1. Image of Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) Virions Taken by the National Institutes of Allergy and Infectious Diseases (NIAID). Note: Image 1.1 depicts a transmission electron microscope image of the SARS-CoV-2, the virus that causes COVID-19 disease, isolated from a patient in the United States of America. Virus particles are shown emerging from the surface of cells cultured in the lab. The spikes on the outer edge of the virus particles give coronaviruses their name, crown-like. Image captured and colorised at NIAID's Rocky Mountain Laboratories in Hamilton, Montana.**

SARS-CoV-2 took to go from an animal host to humans remains unknown. However, the most plausible transmission pathway appears to be from a bat to a pangolin and then to a human ([Hu et al., 2021](#); [Kirtipal et al., 2020](#); [Nadeem et al., 2020](#); [Ye et al., 2020](#)) (see [Fig. 1.1](#)).

There are several different ways that SARS-CoV-2 can transmit between humans. As [Harrison et al. \(2020\)](#) illustrate, human-to-human transmission can occur through contact with faecal matter, droplets on surfaces and airborne respiratory droplets. Airborne respiratory transmission is usually most efficient in cold environments, and SARS-CoV-2 can remain on stainless steel and plastic surfaces for up to 72 hours after application ([Valencia, 2020](#)) (see [Fig. 1.2](#)).

During December 2019 in Wuhan, China, a group of people were diagnosed with atypical pneumonia, with the first known case being diagnosed on 1 December 2019. Most of the patients in this group had a connection to the Huanan Seafood Market, which implies that the then unknown virus had a zoonotic origin. On 30 January 2020, the World Health Organisation (WHO)

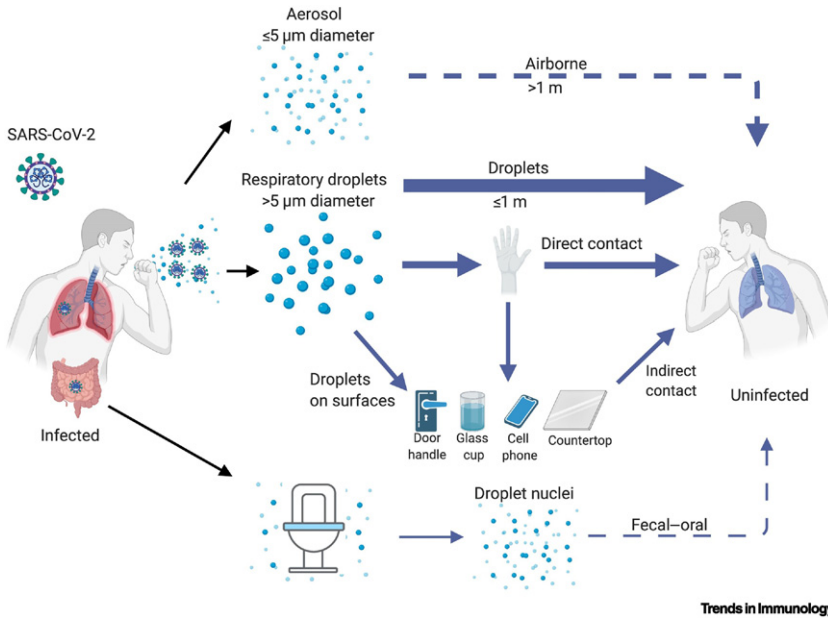


Source: Kirtipal et al. (2020, p. 5).

**Fig. 1.1. Cross-Species Transmission Pathways for Three Coronavirus Virions.**

declared this medical event a ‘public health emergency of international concern’. The WHO then re-classified this event as a global pandemic on 11 March 2020. Prior to its naming, SARS-CoV-2 was called the ‘2019 novel coronavirus’. To avoid any confusion with regards to SARS-CoV, which was first identified in 2002, it was suggested that it should be called ‘human coronavirus 2019’. However, the final and official name of the newly discovered virus was SARS-CoV-2 (Valencia, 2020; Yan et al., 2020).

People who are infected with SARS-CoV-2 and who exhibit symptoms are diagnosed with coronavirus disease (COVID-19). Symptoms can vary between

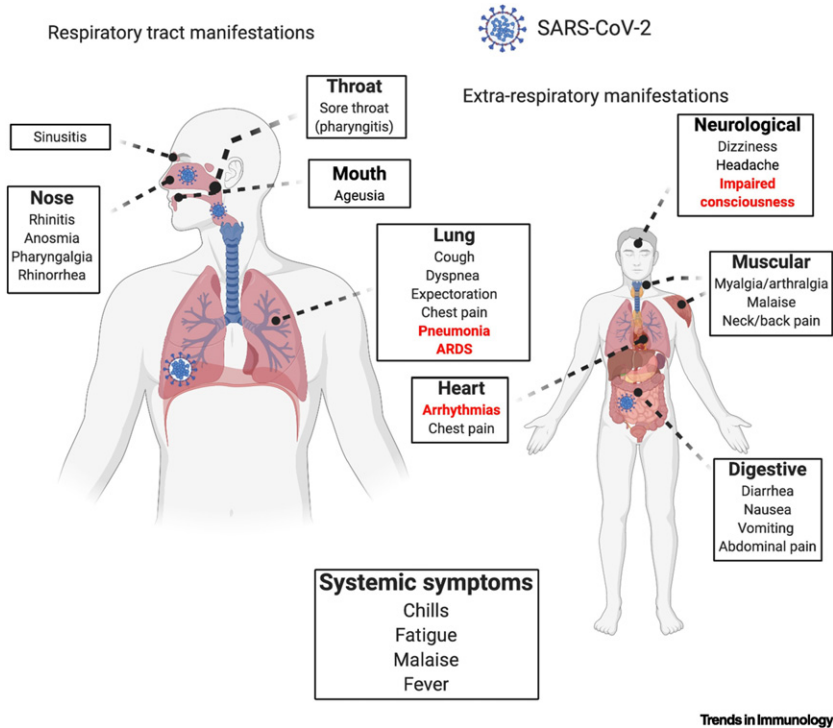


Source: Harrison et al. (2020, p. 1104).

**Fig. 1.2. Transmission Pathways for Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2).**

people, but the main symptoms include fever, chills and a dry cough, sputum production, fatigue, lethargy, arthralgias, myalgias, headache, dyspnoea, nausea, vomiting, anorexia and diarrhoea (Harrison et al., 2020) (see Fig. 1.3). Once infected some individuals may be asymptomatic whilst others will experience either acute respiratory distress syndrome or death. Advanced age and pre-existing chronic medical conditions can increase the severity of a person's COVID-19 symptoms. After infection, the incubation period for SARS-CoV-2 is typically 5.2 days with 97.5% of those infected with this virus developing symptoms within 11.5 days (Valencia, 2020).

During late 2020, different countries approved vaccines that can prevent people developing serious COVID-19 disease after contracting SARS-CoV-2. Pfizer/BioNTech, Moderna, Sputnik V and Oxford–AstraZeneca are common vaccines that have been approved for usage. Doroftei et al.'s (2021) mini-review of 11 studies about the efficiency of COVID-19 vaccines showed that Pfizer/BioNTech (~95%), Moderna (~94%) and Sputnik V (~92%) had an efficacy rate of >90% while Oxford/AstraZeneca had a lower efficacy rate (~81%). Additionally, they could not evaluate the efficacy of Convicidea (AD5-nCoV),



Source: [Harrison et al. \(2020, p. 1105\)](#).

**Fig. 1.3. Common Symptoms of COVID-19 Disease.**

Johnson & Johnson (Ad26.COV2.S), Sinopharm (BBIBP-CorV), Covaxin (BBV152), and Sinovac (CoronaVac).

The COVID-19 pandemic has caused an unexpected and unprecedented disruption to our society and economy. With the widespread requirement to wear masks and practice social distancing, the ways that we perform our daily activities have profoundly changed. There has been widespread debate and discussion, especially within policy and academic spheres, about the social and economic impacts of the COVID-19 pandemic on the public. However, since the combination of COVID-19 and autism research is a niche field, not much literature about the impacts of this pandemic on autistics and their families has been published. To our knowledge, this book is either the first or one of the first to present a synthesis of peer-reviewed academic literature about some of the known impacts of the COVID-19 pandemic on autistics and their families. It is also arguably one of the first to summarise the gaps in our understanding about this topic and to then present new insights about this once-in-a-century public health crisis.

## 1.2 THE INTENDED AUDIENCE FOR THIS BOOK

### 1.2.1 Autistic Adults

There are three reasons why this research is of benefit to autistics. First, autistics will learn what they can expect during the continuing COVID-19 pandemic, especially after reading section ‘3.3 – What impacts has the COVID-19 pandemic had on autistics?’ Equipped with this information they may be able to encounter this pandemic more confidently knowing that their experiences are common for other autistics. Second, this book can be a ‘springboard’ that can help autistics find additional information about the COVID-19 pandemic. Third, autistic and non-autistic parents can acquire an understanding about what they might encounter during the COVID-19 pandemic, especially after reading section ‘3.2 – What are the experiences of the COVID-19 pandemic from the perspective of parents raising autistic children?’

### 1.2.2 Professionals Who Support Autistics

Medical professionals have repeatedly expressed their concerns about the difficulties they confront when supporting autistic patients (Adams & Young, 2020; Calleja et al., 2020; Malik-Soni et al., 2022; Mason et al., 2019; Muskat et al., 2015; Nicolaidis et al., 2015; Raymaker et al., 2017; Unigwe et al., 2017). Adams and Young (2020) reviewed 12 studies about the barriers and enablers that autistics have experienced when they were trying to access psychological treatments. The most cited barrier was a lack of knowledge or unwillingness on behalf of the therapist to tailor their approaches to the autistic client. These results were also echoed by Nicolaidis et al. (2015), who reported that providers’ lack of knowledge about autistic adults as well as incorrect assumptions about autistic patients prevented autistics from obtaining effective medical care. It is plausible to assume that since medical professionals have difficulties assisting autistics, they would also have difficulties assisting them during the COVID-19 pandemic. After reading this book, medical professionals should be able to develop an understanding of some of the challenges that autistics are experiencing during the COVID-19 pandemic. They will also learn about some of the challenges that the families of autistic children are encountering during this pandemic. Armed with this information, medical professionals should be able to tailor their approaches to provide more effective support.

### 1.2.3 Students and Scholars Who Study the Autism Spectrum

Those attending higher education institutions would find this book a valuable source of information. Its contents can help students studying medicine, psychology or social work develop an understanding about some of the challenges that autistics are encountering during the ongoing COVID-19 pandemic. These and other students could also learn about some of the challenges that parents raising autistic children are encountering during this pandemic. For academics, this book can provide them with two benefits. First, they can use its contents to teach their students about the impacts of the ongoing COVID-19 pandemic on autistics. Second, academics can cite the gaps in this field of research, which are outlined in chapter three, in their research activities and grant applications.

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