



Guiding support for family carers

**Covid-19 and
the Impact on
Family Carers**

**A Review of
Recent Research
September 2020**

1. Introduction

The year 2020 has been, and continues to be, a challenging year for family carers, the people to whom they provide care, and the organisations seeking to support them. The rapidly changing circumstances to which people in Ireland and globally have been adapting have taken a toll on every part of society. However, family carers the world over have been particularly negatively affected given that those they care for, many of whom have underlying health conditions, are acutely vulnerable to the disease and more likely to experience serious complications and/or death.

The purpose of this document is to provide an overview of the impact of Covid-19 on Ireland's 391,000 family carers. This paper will examine key rapid surveys and research studies which have been conducted by various researchers and organisations both in a specifically Irish context and internationally. This should not be seen as an exhaustive examination but as a useful overview – we recommend consulting the original research publications for full details. Links are provided where available to direct readers to the full texts.



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While information is correct at time of publication (September 2020), the Covid-19 situation can change swiftly, and knowledge of the disease is evolving daily, and this overview should be read with that caveat in mind. The International Journal of Care and Caring plans to issue a full edition on Covid-19 in August 2021 and we are also aware of longitudinal and more detailed research taking place on topics related to family carers and Covid-19. However, as many of these will not be published for some time, we decided to focus on synthesising currently available research to inform policy makers, service providers and other stakeholders of the issues facing family carers in the era of Covid-19.



Covid-19 in Ireland

To give a brief overview of the Covid-19 timeline here in Ireland, the key dates are set out here:

- 27 January** National Public Health Emergency Team (NPHE) for Covid-19 formed within the Health Service Executive (HSE).
- 29 February** First confirmed case of Covid-19 in the Republic of Ireland.
- 6 March** Visiting restrictions in place across private and voluntary nursing homes.
- 11 March** First fatality in Ireland from Covid-19.
- 12 March** Government announced that all schools, colleges and childcare facilities were to be closed. This included many respite services, day centres and other services that people with disabilities, older people, people with dementia and other conditions accessed on a regular basis. In many cases, these services, as well as providing care to those directly supported, enabled family carers to take a break from caring responsibilities, or to undertake paid employment or household tasks, to visit friends and family, etc.
- 18 March** Care Alliance Ireland created the Family Carer Support Group Ireland via the Facebook platform. This online platform was chosen in order to 'go where carers were' and to get information to family carers quickly, avoiding rumour and hearsay.
- 24 March** Almost all businesses, venues, facilities and amenities were shut.
- 27 March** All 'non-essential' travel and contact with people outside the home (including family and partners) were banned. People aged 70 years and over and those with certain health conditions were advised to 'cocoon' – which meant restricting movements and contact with individuals outside their household.
- 2 April** Agreement reached between HSE and Home and Community Care Ireland to facilitate the redeployment of home care workers into the residential care sector.
- 18 May** Government easing of restrictions began.
- 29 July** Government published the Roadmap for Reopening Disability Services.
- August** As cases rose again significantly, there has been some local and national reversal of the earlier relaxation of the restrictions.

Key Issues

While family carers across Ireland and internationally currently face a significant range of issues, research points to a number of key categories into which the issues can be grouped. As previously stated, we recommend consulting the original research in order to better understand the impact of Covid-19 on family carers.

Practical Issues

Starting on a purely practical note, the everyday lives of family carers changed drastically, virtually overnight in many cases. All at once, not only were health and social care services for those being cared for shut or significantly curtailed, but other services and supports family carers relied on were also impacted.



Caregivers in remote areas with limited access to shops and services were also at a significantly increased risk of mental health difficulties

Access to vital supplies

- In the early weeks of the pandemic and subsequent lockdown, it was difficult to obtain vital supplies such as incontinence pads, cleaning materials, disinfectants, etc.¹ This was due to both restricted supply lines and resource 'hoarding'. As many family carers and those they care for are dependent on state welfare payments for income, many have devised a weekly or fortnightly budgeting/supply purchase system in line with those payments.² These carers were unable to bulk-buy items in advance. Cocooning added to the challenges of purchasing supplies. Twenty-six per cent of Irish family carers worry about obtaining essential supplies.³

¹ The Alzheimer Society of Ireland, 'Covid-19: Impact & Need for People With Dementia and Family Carers'.

² In addition, many social welfare payments were switched to a fortnightly schedule to minimise numbers attending post offices, etc. to pick up payments. As of September 2020 many of these payments have returned to their weekly schedule; however, Carer's Allowance and Carer's Benefit remain on a fortnightly schedule.

³ Family Carers Ireland, 'Caring Through COVID: Life in Lockdown'.



“Shopping for groceries is a nightmare. Have the stress of looking online daily for a delivery slot. We’re cocooning as the person I care for is immunocompromised.”⁴

- In the UK, adequate access to food was highlighted as a significant concern – upwards of 60% of family carers (in April 2020) were having difficulties securing adequate and appropriate food and/or cleaning and hygiene products.⁵

“Sometimes I haven’t been able to get sanitary pads, soap, hand gel and antibacterial spray that I needed for the person I care for.”⁶

- Given the highly intimate care being provided by family carers, often to more than one person, many family carers required some level of personal protective equipment (PPE) to protect themselves and others from contracting or passing on the virus.⁷ Research from Family Carers Ireland found that 47% of family carers were unable to access appropriate PPE during the outbreak.⁸



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Cocooning

- On 27 March, then Taoiseach Leo Varadkar announced ‘cocooning’ measures, similar to the ‘shielding’ advice in other jurisdictions. As part of this ‘cocooning’ phase, members of the public who were medically vulnerable to Covid-19 (including people aged 70 years and over, people with life-limiting conditions, and people who were immunosuppressed

⁴ Family Carers Ireland, ‘Caring Through COVID: Life in Lockdown’, p. 1.

⁵ Carers UK, ‘Caring behind Closed Doors: Forgotten Families in the Coronavirus Outbreak’.

⁶ Carers UK, ‘Caring behind Closed Doors: Forgotten Families in the Coronavirus Outbreak’, p. 18.

⁷ World Health Organization, ‘Preventing and Managing COVID-19 across Long-Term Care Services: Policy Brief’.

⁸ Family Carers Ireland, ‘Caring Through COVID: Life in Lockdown’.

or immunocompromised) were advised to essentially remain at home, with outside activity restricted to back gardens and essential medical appointments. For many this meant relying on family, friends or local volunteers to deliver essentials such as food and medical supplies.

- For carers who do not live with the person they care for, cocooning meant an increase in responsibilities. Many needed to travel outside the then 2km travel limit, and to manage shopping and other tasks. Indeed, many adult children overnight took on a degree of ‘caring’ for their parents that had not previously been required.
- Many family carers chose to cocoon with the person they care for to minimise exposure risks, with a consequent reduction in their own social and leisure activities outside the home. In many cases, carers became completely cut off from daily life.⁹ Some remain voluntarily cocooning, even as restrictive measures are lifted across the country. However, as advice regularly changes in response to shifts in Covid-19 prevalence within the community, it is possible that all family carers and those they care for will be required to isolate at various times over the coming months.



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Increased demand for services carers rely on

- Related to the above, family carers who chose to or who had to cocoon for their own or others’ safety found themselves relying on online shopping and deliveries for groceries, medical supplies, prepared food and household necessities. Many suppliers were unable to meet this sudden increase in demand. Family carers have seen their usual routines greatly disrupted by the impacts of Covid-19.

⁹ The Alzheimer Society of Ireland, ‘Covid-19: Impact & Need for People With Dementia and Family Carers’.



- A number of stores and services responded to the needs of people cocooning by reserving timeslots for those deemed 'at-risk'. However, there was confusion among carers as to which stores required proof of family carer status and concerns about how that might be evidenced.



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Decisions on home care services

- In the early days of the pandemic, family carers were faced very suddenly with having to make extremely difficult decisions regarding whether or not to continue availing of state home care hours for the person they provide care to. Low levels of understanding about the virus and high levels of fear and confusion regarding its spread, coupled with lack of clarity on the use of PPE and the scarcity of PPE for community (non-hospital) use led to some family carers choosing to temporarily discontinue home care hours. According to Family Carers Ireland 14% of family carers completely cancelled home care for the person they care for.¹⁰



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*"I chose to cancel all home supports in March as I am so fearful of Covid-19 coming into our home. I do not have a back-up plan should I get sick. There is simply nobody to take over from me."*¹¹

¹⁰ Family Carers Ireland, 'Caring Through COVID: Life in Lockdown'.

¹¹ Family Carers Ireland, 'Caring Through COVID: Life in Lockdown', p. 8.

“We cancelled the home care as the risk was so high with the home carer visiting up to ten homes in any day, and we were not sure if their PPE was adequate”.¹²

- In April the HSE established a protocol for the redeployment of home care workers to nursing homes due to the increased workload in the residential sector arising from Covid-19 clusters. This was predicated on the assumption that family supports would mitigate the withdrawal of services. The HSE has reported to the Oireachtas Special Committee on Covid-19 that home care was suspended for more than 11,000 people, of whom 7,500 requested the suspension. The remaining 3,800 had their home care temporarily suspended by the HSE. As a result the workload of family carers was increased.¹³
- Some 36% of family carers experienced a reduction or cancellation of home care services.¹⁴ This, not surprisingly, has led to an increase in the workload for family carers on a daily basis.¹⁵ In research by Carers UK, 70% of family carers reported providing more care since the outbreak of Covid-19;¹⁶ according to The Alzheimer Society of Ireland, 77% of family carers of people with dementia have seen an increase in the level of care they provide.¹⁷ Research with young carers in Scotland has shown that one in ten have seen their caring responsibilities increase by 30 hours or more due to Covid-19.¹⁸



77% of family carers of people with dementia have seen an increase in the level of care they provide

“I find I am doing more for her and this is very tiring, not because of the work but more of the mental challenges that I come up against each day. I find it very draining.”¹⁹

¹² The Alzheimer Society of Ireland, ‘Caring and Coping with Dementia During Covid-19’, p. 10.

¹³ Pierce, Keogh, and O’Shea, ‘The Impact of COVID-19 on People Who Use and Provide Long-Term Care in Ireland and Mitigating Measures’.

¹⁴ Family Carers Ireland, ‘Caring Through COVID: Life in Lockdown’.

¹⁵ World Health Organization, ‘Preventing and Managing COVID-19 across Long-Term Care Services: Policy Brief’.

¹⁶ Carers UK, ‘Caring behind Closed Doors: Forgotten Families in the Coronavirus Outbreak’.

¹⁷ The Alzheimer Society of Ireland, ‘Caring and Coping with Dementia During Covid-19’.

¹⁸ Carers Trust Scotland, ‘2020 Vision: Hear Me, See Me, Support Me And Don’t Forget Me. The Impact of Coronavirus on Young and Young Adult Carers in Scotland, and What They Want You to Do Next’.

¹⁹ The Alzheimer Society of Ireland, ‘Caring and Coping with Dementia During Covid-19’, p. 10.



- International research supports these results, with research undertaken by Oxfam in five countries (USA, Canada, Great Britain, the Philippines and Kenya) showing increases in both men's and women's domestic labour (not strictly family care responsibilities); in the USA, 55% of women and 64% of men reported spending more time on domestic and care tasks.²⁰

Continuing care

- A consistent theme throughout research to date has been significant worry and fear among family carers regarding contracting Covid-19. This includes fear for both the person they provide care to and themselves.

*"I am terrified, to the point of suffering a panic attack, that either Mum or I will become infected and I'll either have to battle to keep her isolated, or worse I might get ill and won't be able to keep her safe because I'll have to self-isolate."*²¹

- 84% of respondents to a survey by Family Carers Ireland reported being worried about getting the virus and being unable to care for their loved one.

*"I am terrified that I will get Covid-19. There is no one else to fill my role. What happens then? Not knowing keeps me awake at night. When I do sleep, it gives me nightmares. The uncertainty fills me with fear."*²²

- Others worry about being able to accompany their loved one into hospital if an admission is required – confusion as to whether this would be allowed under the restrictions was a common theme.

*"I'm worried that my mother would have to go to hospital and I may not be allowed to accompany and care for and advocate for her whilst there. I care for her 24/7. She needs assistance mobilising with frame, washing, toileting, getting up and down, administering medicines, etc. She would be hugely distressed and lost and confused in a hospital on her own and unable to communicate sufficiently with doctors or nurses."*²³

²⁰ Bolis et al., 'Care in the Time of Coronavirus - Why Care Work Needs to Be at the Centre of a Post-COVID-19 Feminist Future'.

²¹ Carers UK, 'Caring behind Closed Doors: Forgotten Families in the Coronavirus Outbreak', p. 14.

²² Family Carers Ireland, 'Caring Through COVID: Life in Lockdown', p. 9.

²³ Family Carers Ireland, 'Caring Through COVID: Life in Lockdown', p. 13.

Health Impacts

A very clear theme throughout the research published to date is the impact of the pandemic on the physical and mental health of both family carers and those they care for.

Impact on health of cared-for person

- Family carers have reported that they feel that the person they provide care to has either stopped making progress or has begun to disimprove throughout this time. Some 63% of family carers are worried about a decline in the health and wellbeing of the person they provide care to²⁴ and research from The Alzheimer Society of Ireland specific to those caring for a person with dementia saw that number rise to 86%.²⁵



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- This disimprovement is a particular concern given that for some conditions, such as Alzheimer's disease and other forms of dementia, this regression may prove permanent or at best difficult to counteract, especially given that many community-based services will be unable to operate at full capacity for the foreseeable future. This situation is causing family carers considerable upset as they feel they are 'losing time' with their loved ones.

*"Decline cognitively with loss of daycare supports, with reduction in social contact, change in routine and disconnect with other family members that probably is lost permanently now, even when cocooning ceases."*²⁶

²⁴ Family Carers Ireland, 'Caring Through COVID: Life in Lockdown'.

²⁵ Alzheimer Society of Ireland, 'Caring and Coping with Dementia During Covid-19'.

²⁶ Alzheimer Society of Ireland, 'Caring and Coping with Dementia During Covid-19', p. 11.



- A quote from a family carer responding to research from Family Carers Ireland highlights this across the spectrum of caring:

“I think his inability to continue his outings (bridge, church, community dinner) has increased his dependency on me and I think this will be irreversible. I think my caring role will be more full-time from now on. My availability to work will be diminished. Because I don’t qualify for Carer’s Allowance, this is difficult.”²⁷



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- As health services either curtailed their routine services or had to redeploy staff to other parts of the health service, many routine appointments and services were impacted. Research from The Alzheimer Society of Ireland indicated that 60% of family carers experienced the cancellation or postponement of medical appointments due to Covid-19.²⁸

Impact on health and wellbeing of family carers

- Across the board, the research has highlighted concerning health impacts of Covid-19 for family carers.
- Research from the University of Limerick and Northumbria University (UK) suggests that family carers are at increased risk of depression as a result of Covid-19.²⁹
- 61% of respondents to an Alzheimer Society of Ireland research report are concerned about a decline in their own mental health and wellbeing³⁰ – mirrored almost exactly (60%) by respondents to a similar question posed by Family Carers Ireland.³¹

²⁷ Family Carers Ireland, ‘Caring Through COVID: Life in Lockdown’, p. 7.

²⁸ Alzheimer Society of Ireland, ‘Caring and Coping with Dementia During Covid-19’.

²⁹ Gallagher and Wetherell, ‘Risk of Depression in Family Caregivers’.

³⁰ Alzheimer Society of Ireland, ‘Caring and Coping with Dementia During Covid-19’.

³¹ Family Carers Ireland, ‘Caring Through COVID: Life in Lockdown’.

- Studies on loneliness and isolation of family carers have reported large numbers of respondents who report experiencing increased loneliness as a result of Covid-19:
 - 54% of respondents to an Alzheimer Society of Ireland study reported experiencing loneliness and isolation.



54% of respondents to an Alzheimer Society of Ireland study reported experiencing loneliness and isolation

- 37% of respondents to a Family Carers Ireland study reported worrying about becoming more socially isolated as a result of Covid-19.
- 74% of young carers reported feeling less connected to others than they did before the pandemic.
- 45% of young carers (under 18) and more than 2 in 3 (68%) young adult carers (18–24) in Scotland say their mental health is worse than it was before the pandemic began.

“Anxiety has dramatically increased and find myself crying at night and don’t know why.”³²

- The physical health of family carers has also been impacted by the various measures; for example, 35% of young carers are struggling to look after themselves – to eat healthily, exercise or get enough sleep. This rises to 59% among young adult carers.³³ Similarly, 36% of family carers of people with dementia in Ireland are worried about a decline in their own health.³⁴

³² Carers Trust Scotland, ‘2020 Vision: Hear Me, See Me, Support Me And Don’t Forget Me. The Impact of Coronavirus on Young and Young Adult Carers in Scotland, and What They Want You to Do Next’, p. 8

³³ Carers Trust Scotland.

³⁴ The Alzheimer Society of Ireland, ‘Caring and Coping with Dementia During Covid-19’.



Carer Anger and Frustration

It is very clear from the research that family carers feel angry, frustrated and disappointed by the response – or lack thereof – to these issues, from government in particular.

Carers feel forgotten

- Throughout the pandemic, great levels of public acknowledgement for frontline health workers has been evident – and with good reason. However, in ‘normal’ times family carers are the cornerstone of care and provide approximately €10 billion worth of care to the economy per year, a significant amount by any standards. Family carers have felt forgotten throughout the pandemic.
- 74% of respondents to a survey by Family Carers Ireland feel the Government has not responded well to the needs of family carers.

“I feel forgotten and invisible by our Government. It’s only a matter of time before the Government makes cuts to services, supports, allowances, medical cards, etc. I wonder will I be able to continue to care? I’ve my own health concerns, will I make it? Will I be here to care when Covid is over?”³⁵



I feel forgotten and invisible by our Government. It’s only a matter of time before the Government makes cuts to services, supports, allowances, medical cards, etc

³⁵ Family Carers Ireland, ‘Caring Through COVID: Life in Lockdown’, p. 15.

Lack of communication from government

- A significant complaint from the research across jurisdictions is the relatively low level of communication from government to family carers.³⁶

“There’s a lack of a clear plan by the Government on how families like mine would be helped if the carer is ill and needs to self-isolate. There is no plan.”³⁷

- For others, the information is there but it does not appear accurate or complete.

“The advice being given regarding self-isolating/shielding is confusing. Government are claiming things are happening to support more vulnerable people when clearly they are not happening. I’m very reluctant to turn to GPs as they are being overwhelmed with queries. So many people are being let down.”³⁸

- The delay in publishing a roadmap for the reopening of disability and related services (published on 28 July) has been a source of great frustration, in particular when contrasted with the level of support being given to businesses like restaurants and pubs to open safely.

“Carers are at breaking point. With no idea of when services will be back, carers can’t see a light at the end of the tunnel and they really need one. Carers are suffering with depression and no services, experiencing a huge loss of identity, purpose, and role.”³⁹

³⁶ Carers NSW, ‘Covid-19 and Carers: A Review of the Evidence’.

³⁷ Family Carers Ireland, ‘Caring Through COVID: Life in Lockdown’, p. 9.

³⁸ Carers UK, ‘Caring behind Closed Doors: Forgotten Families in the Coronavirus Outbreak’, p. 19.

³⁹ The Alzheimer Society of Ireland, ‘Caring and Coping with Dementia During Covid-19’, p. 18.



Suggested Responses

As we enter a new phase of the pandemic, we can learn from this new research. It is likely that Covid-19 will be with us for a significant period of time. In this context it is important that as cycles of infection and recovery take place, we understand how to include family carers in planning, advocacy, research and communication regarding the disease. Many of the research reports mentioned have outlined specific responses suggested by family carers themselves, including:

- Service recommencement as soon as possible, with support and additional funding where required from government.
- Creation of online spaces for family carers accessible to all.
- Acknowledgement, beyond words, of the work being done by family carers to enable the work of the health service. This should include the addition of family carers to the frontline workers category and to the list of priority groups as regards government policy. Full access to PPE equipment should be ensured.
- Creation and funding of additional mental and physical health supports for family carers who have been disproportionately affected by the restrictions and health implications of Covid-19.
- Clearer, direct communication with family carers on all relevant aspects of measures that affect carers, and updates as the measures change. This communication should be included at the government press briefings rather than as an incidental document or press release.
- Increased clarity on issues such as accompanying the cared-for person to medical appointments. Information must be standardised across hospitals, and all staff (both medical and support staff) must be made aware of the needs of family carers and those they care for.
- Increased financial support to minimise the financial burden of Covid-19 on family carers.

Conclusion

This report has provided a brief overview of some of the key issues that have emerged from the early research/surveys with family carers throughout the Covid-19 pandemic. The pandemic is not over; however, as we emerge from the initial emergency situation into a period of managing the effects while the search for a vaccine or treatment which could enable a return to more normal life continues, we need to learn from the research already conducted. We encourage service providers, policy makers and health and social care professionals to listen to the issues and concerns of family carers, and to solve those problems by making the necessary adjustments to the health and social system.

It is clear from the research profiled in this document, which comes from a number of countries including Ireland, the UK, Australia and others, that the same key issues are facing family carers the world over, with even more significant difficulties facing carers in developing nations. This suggests that no government is currently getting it completely right when it comes to supporting and communicating with family carers.

We encourage readers to read the original research referenced here to understand the true scope of the difficulties faced by family carers at this time. For some carers, life goes on much the same as before, because for them isolation and difficulty obtaining support have been the norm, but they now have added difficulties. For many carers and those they care for, the restrictions, the fear and the closure of services they previously relied upon are causing immense distress.



We encourage service providers, policy makers and health and social care professionals to listen to the issues and concerns of family carers, and to solve those problems by making the necessary adjustments to the health and social system



Key Research Publications

As mentioned, this overview report is based on a number of key research publications. These are available in open access formats for consultation.

Caring Behind Closed Doors – The Forgotten Families in the Coronavirus Outbreak. Carers UK (<https://bit.ly/2GhUOX1>)

Covid-19: Impact & Need for People with Dementia and Family Carers. Alzheimer Society of Ireland (<https://bit.ly/31X9H9P>)

Caring and Coping with Dementia During COVID-19. Alzheimer Society of Ireland (<https://bit.ly/2DubhXe>)

COVID-19 and carers. Carers NSW Australia (<https://bit.ly/2EXNgbD>)

Care, Poverty and Coronavirus across Britain. Oxfam UK (<https://bit.ly/3jJnIDg>)

Care in the Time of Coronavirus – Why Care Work Needs to Be at the Centre of a Post-COVID-19 Feminist Future. Oxfam UK (<https://bit.ly/3jN017B>)

2020 VISION: Hear Me, See Me, Support Me and Don't Forget Me: The impact of coronavirus on young and young adult carers in Scotland, and what they want you to do next. Carers Trust Scotland (<https://bit.ly/2ELSAPy>)

Risk of Depression in Family Caregivers: Unintended consequence of COVID-19. Stephen Gallagher & Mark A. Wetherell (<https://bit.ly/2Z1OIWX>)

Social Implications of COVID-19 in Ireland – Preliminary Assessment. Govt of Ireland, Dept of the Taoiseach (<https://bit.ly/3bn4kng>)

Caring through COVID: Life in Lockdown. Family Carers Ireland (<https://bit.ly/3hVOFYn>)

Preventing and managing COVID-19 across long-term care services: policy brief. World Health Organization (<https://bit.ly/3IOESf5>)

The impact of COVID-19 on people who use and provide long-term care in Ireland and mitigating measures. Pierce M, Keogh F and O'Shea E (<https://bit.ly/32RIEgk>)

The invisible workforce during the COVID-19 pandemic: Family carers at the frontline [version 1; peer review: 2 approved]. Phillips D, Paul G, Fahy M et al. HRB Open Res 2020 (<https://bit.ly/31VVDgQ>)

Acknowledgements

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This first edition is to be published in September 2020, and will be updated as new research emerges. The most recent version of this document will be available on the Care Alliance website (www.carealliance.ie).

We acknowledge the research referenced in this document, in particular the research by Family Carers Ireland and The Alzheimer Society of Ireland. This report should be seen as an overview of key points from the original research. We encourage readers to refer to the original research for full details, in-depth analysis and discussion, and recommendations which could not be accommodated in this overview.

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