A GUIDE FOR EVERYONE

Write to your MP about FASD

Using the Cost of Inaction on FASD findings to get action where you live

> **You do not need to be an expert. You do not need to share anything personal. You do not need to know how Parliament works.**
>
> This guide gives you the words, the numbers and a ready-to-send email. Copy what is useful, ignore the rest. Most people can do this in about twenty minutes — everything after the first page is extra help.

Start here: the short version

If you only read one page, read this one.

What to remember	In plain words
The problem	Fetal Alcohol Spectrum Disorder (FASD) is one of the most common conditions affecting how the brain develops, and one of the least recognised. Big government reforms in health, education, benefits, justice, social care and homelessness are being designed without mentioning it.
The cost	Doing nothing is expensive. We estimate around £9.2 billion a year, and around £160 billion over 30 years, because help arrives late and in crisis rather than early.
The solution	A four-nation FASD Prevention and Response Programme, paid for with the equivalent of 0.25% of alcohol duty receipts. That is a small slice of money already collected.
Your ask	Ask your MP to write to the Secretary of State for Health and Social Care supporting that programme.

Three steps

1. Find your MP's email address on the UK Parliament website, or book a place at their next surgery.
2. Use the ready-to-send email in this guide. Change the bits in square brackets so it sounds like you.

3. If they reply, say thank you and ask for one specific next step — a letter, a written question, or a meeting.

The three numbers to quote

MPs and their staff read quickly. These three figures do most of the work for you.

Figure	What it means
£9.2 billion a year	Our estimate of what FASD costs UK society every year when it is not identified and supported.
£160 billion over 30 years	The same problem left alone for a generation, expressed in today's money.
0.25% of alcohol duty receipts	What we are asking Government to set aside to fund prevention, diagnosis, support, training and research across all four nations.

Why the money is being spent badly

Our argument is not that too little money is spent on FASD. It is that the money is already being spent — just at the wrong moment and in the wrong place.

- Spent late — after a crisis, instead of through early identification.
- Spent in crisis — emergency health, justice or care responses instead of planned support.
- Spent in the wrong places — because nobody recognised what was going on early enough.

We call this unplanned spend. The spending is real and it is happening now. What is avoidable is the lack of planning.

Where these numbers come from — and why UK research is needed

We want you to feel confident using these figures, and equally confident explaining their limits. Being straight about this makes you more persuasive, not less.

How we built the estimate

- The starting point is a widely accepted and widely cited US study of the economic impact of FASD by Greenmyer and colleagues (2018), which put the lifetime cost at around US$596,000 per person.[1]
- We converted that to 2024 pounds using a recognised health-economics method for moving costs between countries and price years, published by Shemilt and colleagues (2010) and used in NICE-related work.[2]
- We then applied HM Treasury Green Book rules, including the standard 3.5% discount rate, so the long-run figures follow the same conventions Government itself uses.[3]
- We assumed only about one in ten people with FASD is currently diagnosed, and that undiagnosed cases cost around 20% more. That 20% figure is a stated working assumption, not a measured result.
- Family and carer costs are largely left out, so if anything the total understates the picture.

We used AI, and we say so

The report and our local models were created with the help of Perplexity AI. All figures, calculations and citations were checked against the published sources. Our spreadsheet models are available on request, so anyone can check a number or re-run it. Our note on methodology sets this out in full.

> **The honest headline: this is a careful UK estimate built on US evidence.**
>
> There has never been a proper UK-wide study of how many people have FASD and what it costs. That gap is exactly why Government can keep treating FASD as somebody else's problem. We have put forward a sample funding proposal showing how this work could be built — a lean, virtual-first programme of eight expert roundtables running from September 2026 to March 2027, leading to a policy-ready report and a costed case for a UK prevalence study and a standing research fund. Ask your MP to back UK research, not just to accept our numbers.

If your MP challenges the evidence, that is a good conversation, not a bad one. The answer is: fund the UK research so we can stop borrowing American figures.

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[1] Greenmyer, J. R., Klug, M. G., Kambeitz, C., Popova, S., & Burd, L. (2018). A multicountry updated assessment of the economic impact of fetal alcohol spectrum disorder: Costs for children and adults. Journal of Addiction Medicine, 12(6), 466–473. https://doi.org/10.1097/ADM.0000000000000438

[2] Shemilt, I., Thomas, J., & Morciano, M. (2010). A web-based tool for adjusting costs to a specific target currency and price year. Evidence & Policy, 6(1), 51–59. https://doi.org/10.1332/174426410X482999

[3] HM Treasury. (2022). The Green Book: Central government guidance on appraisal and evaluation (3.5% social time preference discount rate). https://www.gov.uk/government/publications/the-green-book-appraisal-and-evaluation-in-central-governent

Want the numbers for your own area?

National figures open the door. Local figures keep your MP's attention. We can model the picture for a local authority, an NHS footprint or a constituency — how many young people in one age group are likely to have FASD, the projected lifetime cost, and the unplanned spend created by the diagnosis gap.

Join a forthcoming national FASD briefing

We are scheduling a national online briefing on the Cost of Inaction findings, open to families, practitioners, commissioners and campaigners. It will walk through the findings, the four-nation ask, and how to use this material with your own MP and local decision-makers.

If you come along, we can generate the local numbers for your area for you. This is available at cost, on request — just ask us and we will explain what is involved.

To register your interest, email us via nationalfasd.org.uk and mention the local Cost of Inaction on FASD briefing.

What a local model can and cannot tell you

It can say	It cannot say
How many people in an age group are likely to have FASD, based on published prevalence research applied to official population figures.	How many people in your area actually have FASD. Nobody has measured that.
A projected lifetime societal cost for that group, and the share linked to the diagnosis gap.	What your council or NHS body actually spent last year.
A planning figure your MP, council or integrated care board can work with.	A diagnosis count, or a local prevalence study.

Always describe local figures as modelled or projected estimates. Never present them as counted people or observed spending. And please do not divide £9.2 billion by population to invent a local figure — it looks precise and is not.

FASD in plain words

Fetal Alcohol Spectrum Disorder is a lifelong condition affecting how the brain develops, caused by alcohol exposure before birth. It is one of the UK's most under-recognised neurodevelopmental conditions.

People with FASD can find memory, attention, planning, sensory processing, managing emotions and everyday living skills much harder than others expect. Because you cannot see it, it is often missed, misdiagnosed, or misread as bad behaviour — in school, in the benefits system, in the justice system and in adult services.

Please use person-first language when you write: a person with FASD. Nobody "suffers from" FASD, and this is never about blaming mothers.

The gap your MP can help close

Current UK reform programmes across health, education, benefits, justice, social care and homelessness are moving ahead without naming FASD, even though the condition sits squarely inside all of them.[4]

What to ask for

Your main ask

> Please write to the Secretary of State for Health and Social Care — and ideally HM Treasury and the Department for Education — asking the Government to fund and establish a UK-wide FASD Prevention and Response Programme, as costed in National FASD's report.

If that feels like too much, ask for one of these

- Table a written parliamentary question on how the Government is responding to the report.
- Raise FASD in a debate on health, education, justice or the Budget, or ask to meet the Minister.
- Meet local families, clinicians or support organisations to hear directly what happens now.
- Support the call publicly — a constituency newsletter item or a social media post — making clear this is a policy position, not a party one.
- Back the case for UK research, including a proper UK prevalence and cost study.

Why this ask is easy for an MP to say yes to

- It is evidence-based: a published, costed report from the UK's leading FASD charity, with its methods openly available.
- It is proportionate: 0.25% of alcohol duty receipts is modest next to £9.2 billion a year, and needs no new general taxation.

[4]National FASD (2026, 11 June). The Cost of Inaction on FASD: A Critical Gap in Current Reforms. https://nationalfasd.org.uk/the-cost-of-inaction-on-fasd/

- It is timely: it lines up with reform programmes happening right now.
- It is achievable: you are asking for a letter or a question, not a guarantee.

Your ready-to-send email

Change the words in square brackets. Keep it short — shorter emails get read.

> **Subject:** A request from your constituent: the cost of inaction on FASD
>
> Dear [MP name],
>
> I am your constituent, living in [area or postcode]. I am writing about Fetal Alcohol Spectrum Disorder (FASD), a lifelong condition caused by alcohol exposure before birth, and one of the most common yet least recognised conditions affecting how the brain develops.
>
> I am asking you to write to the Secretary of State for Health and Social Care in support of a UK-wide FASD Prevention and Response Programme.
>
> National FASD's June 2026 report, The Cost of Inaction on FASD, estimates that failing to act costs the UK around £9.2 billion a year, rising to around £160 billion over 30 years — largely because support arrives late and in crisis instead of through early identification. The report proposes a proportionate funding mechanism worth the equivalent of 0.25% of alcohol duty receipts.
>
> The estimate is a UK adaptation of respected US research, and National FASD is clear that a proper UK study is still needed. I would also welcome your support for funding that research.
>
> [Optional: one or two sentences about why this matters to you, your family, your school or your service. Share only what you are comfortable sharing.]
>
> I would be glad to discuss this with you or your team, and I can send you the full report.
>
> With thanks,
>
> [Your name] — [Your address and postcode] — [Your contact details]

If they ask you a tricky question

You are allowed to say "I don't know, but National FASD can answer that." Here are short, honest replies to the questions that come up most.

They might say	You can say
Isn't health devolved?	Partly — which is why the report asks for a four-nation programme. Your MP can still write to the UK Government about UK-wide prevention, alcohol duty, and health, education and justice funding in England, and can push for coordination with the devolved administrations.
Where is the proof this saves money?	The case is that late, crisis-driven spending costs more than early identification and support. The full report and its methodology note are available for scrutiny, and the spreadsheet models can be shared on request.
Isn't £9.2 billion just an American figure?	It is a UK adaptation of a widely accepted US study, converted using a recognised health-economics method and Treasury Green Book rules. National FASD says openly that UK research is needed — and has set out how it could be funded. That is part of the ask.
You used AI to write this?	Yes, and it is disclosed. Perplexity AI helped prepare the analysis and materials; every figure, calculation and citation was checked against the published sources, and the models are available so anyone can re-run them.
Isn't this quite niche?	FASD is one of the most common yet least recognised neurodevelopmental conditions in the UK. The ask is about aiming existing reform programmes better, not inventing a new area of policy.

Making it local, honestly

You do not need a local statistic to make this a constituency issue. Build the local link with things that are simply true where you live.

- Every constituency is likely to include a meaningful number of undiagnosed children and adults with FASD — in mainstream schools, in the benefits system, and in local justice and care services.
- Local schools, SEND services, fostering and adoption services and probation are all touched by the reforms that currently overlook FASD.
- Health and wellbeing boards, integrated care boards and council SEND strategies are live decision points where FASD could be named explicitly.
- If you or people you support have direct experience of the diagnosis, school or support gaps, that is powerful. Share only what you choose to share.

An example you can adapt

> *"As your constituent in [area], I am asking you to take up National FASD's June 2026 report, because families and schools across [constituency] are affected by exactly the gaps it identifies — in early diagnosis, school support and joined-up local services — and because the reforms it says are overlooking FASD are the same health, education and social care reforms affecting people here."*

Before a meeting or surgery

- Send info from this guide, or just the first page, in advance.
- Decide your main ask and your fallback ask beforehand.
- Decide what personal information, if any, you want to share. None is required.
- Remember the three numbers: £9.2 billion a year, £160 billion over 30 years, 0.25% of alcohol duty receipts.
- Before you leave, ask for one specific next step and a rough timescale.

MPs can write to ministers, table written questions, speak in debates and raise constituency concerns directly with Government. Contact details are on the UK Parliament member pages.[5]

Afterwards

Send a thank-you within a day or two, while it is fresh. Write down exactly what was promised, and do not overstate support that was not given.

> **Subject:** Thank you — FASD and the Cost of Inaction report
>
> Dear [MP name],
>
> Thank you for meeting me on [date] to talk about FASD and National FASD's report, The Cost of Inaction on FASD.
>
> As we discussed, I am asking you to [write to the Secretary of State for Health and Social Care / table a written question / raise this in a debate] on funding a UK-wide FASD Prevention and Response Programme, and to support funding for UK research.
>
> I have attached the full report and the family action pack. National FASD would be very happy to brief you or your team directly, and can model the FASD picture for our area at cost on request.
>
> With thanks,
>
> [Your name]

[5] UK Parliament. Contact your MP. https://members.parliament.uk/

If you are doing this for an organisation

Writing as a private constituent? You can skip this page. Just make sure your claims are accurate and credited to the report.

If you are acting for a charity or voluntary organisation, check before you send:

- The ask supports your charitable purposes and has the right internal sign-off.
- You can explain the methodology if asked, including that AI was used in preparing the report and that this is disclosed.
- The approach is framed around a policy ask, never support for a party or candidate.
- Any lived-experience story is used only with informed, voluntary consent.

Charities in England and Wales may campaign and engage MPs in support of their charitable purposes, provided they stay independent of political parties and candidates and keep campaigning lawful, accurate and proportionate.[6]

More help from National FASD

All of these can be shared with your MP's office alongside this guide:

- The full report, with visual summaries for each section.
- The Easy Access Report — a plain-language summary of the key findings.
- The note on methodology, explaining how the report was made and how AI was used.
- The media pack — media release, summary, background on FASD and key quotes.
- The family action pack — for raising the findings with NHS bodies, elected representatives or the media.

Everything is on the report page: nationalfasd.org.uk/the-cost-of-inaction-on-fasd

> *"We encourage people to use this report in efforts to promote change."*
>
> Sandy Butcher, Chief Executive, National Organisation for FASD

#FASDCostOfInaction #FASDInvestToSave #FASDGrowsUp #EveryonePlaysAPart

References

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[6]Charity Commission for England and Wales. Speaking out: Guidance on campaigning and political activity by charities (CC9). GOV.UK. https://www.gov.uk/government/publications/speaking-out-guidance-on-campaigning-and-political-activity-by-charities-cc9

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Prepared by the National Organisation for FASD, September 2026. Created with the help of Perplexity AI; all figures, calculations and citations were checked against the sources listed above. Our spreadsheet models are available on request so any figure can be checked and re-run.